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Impairment, Disablement and Identity

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PhD

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Declaration

I declare that the following thesis has been composed by myself and that the work is my own.

Nicholas Thomas Watson

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This thesis would not have been completed without the help and support of a great many people. First and foremost are the research participants who so willingly gave of their time and made the whole process of data collection a pleasure. My supervisors Dr. Sarah Cunningham-Burley and Professor Kath Melia provided me with constant support and advice and without their encouragement this thesis would not have been finished.

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Abstract

Disability is a contested concept. There is little agreement within the social sciences on who disabled people are, what causes disability or on the impact of disability on identity and identity formation. On the one hand, there are those within medical sociology who see disability arising as the outcome of impairment and focus their research and theorising on the trouble that an impairment causes for disabled people. This understanding is based on a normative definition. On the other hand, there are those within disability studies who argue that disablement arises as a consequence of a society that is organised in a way that excludes people with impairments; they focus their research on societal and environmental barriers. In the latter paradigm, any focus on impairment itself is seen as a diversion from the 'real' problem: the discrimination and oppression of disabled people. The impact of impairment, the personal experience of disablement and issues of identity are ignored in favour of radical rhetoric. There is a theoretical deficit at the heart of this approach. In order to address this lacunae the experiences and views of disabled people themselves must inform theoretical developments.

This study involved in-depth analysis of data generated by semi-structured interviews with 28 men and women with a physical impairment. The analysis shows how, for many of the participants in this study, having an impairment did not constitute trouble; impairment has become part of their embodied being. It also shows how disabled people are not an homogenous group, but are individuals. Their understandings, identity and experiences are fluid, contextualised and situated. There is no such thing as 'the disabled' and many reject an identity posited on such criteria. Their main commonality is a common experience of discrimination and oppression. How this discrimination is interpreted is individual; further, impairment and disablement are linked and should not be seen as separate entities.

Such findings create a problem for both disability studies and the disabled people's movement. If disability studies is to account for disability it must explore the issue at an interpersonal level, with impairment neither being ignored, nor separated from disablement. In addition the ever-presence of disabling social relations suggest that a focus on challenging meta-narratives must continue, however, these challenges must be situated and historically contingent. It is only through documentaries of the lives of disabled people that the realities of being a disabled person in the 21st Century will emerge. Disability should be seen not as either the product of an individual trait, the impairment, nor as simply a social product, but as a fluid multiplicity subject to complex structural and interactional processes.

Contents

Declaration	
Acknowledgements	
Abstract	
	Page No.
Introduction	1
The Structure of the Thesis	6
Chapter 1: Theorising Disability	
Introduction	11
Disability as Deviance	12
Disability as Societal Deviance	12
Disability as Bodily Deviance	31
The Conflict Perspective: The Social Model of Disability	33
Conclusion	48
Chapter 2: Theorising Impairment	
Introduction	51
The Body in Disability Studies	52
Materialist Challenges to the Disability Studies Canon	55
Challenging the Categories: Post-structuralism and the social model	56
Experiencing Impairment: Phenomenological Approaches	59
Experiencing Impairment	59
The Body as Taken-for-Granted	63
Embodiment	65
Conclusion	70
Chapter 3: Researching Disability	
Introduction	72
The Disability Studies Research Agenda	73
Researching Impairment	76
Capturing Experience	79
Insider or Outsider	86
Research Method	88
Research Participants	89
Structure of Interviews	90

Chapter 4: Experiencing Impairment

Introduction	95
Capturing the Taken-For-Granted	95
Healthy or Unhealthy/Disembodied or <i>Dys-embodied</i>	98
The Dys-appearance of the Body	106
Dys-appearance and Impairment	106
Dys-appearance and Gender Issues	107
Dys-appearance and Fatigue	108
Dys-appearance and the Environment	109
Relating to the Body	110
The Responsive Body	114
Conclusion	121

Chapter 5: Daily Denials: The Routinisation of Oppression and Resistance

Introduction	123
The Importance of Interaction: Reclaiming social interaction	124
Prejudice	127
The Daily Experience of Oppression	128
Oppression as Patronage and the Denial of Agency	130
Oppression as the Product of Charity	133
Becoming the centre of attention	135
Engaging with non-disabled people	136
Oppression as Ignorance	137
Ignoring Impairment	139
Ignoring or Challenging Ignorance	141
Ignoring Sexuality	143
Conclusion	149

Chapter 6: Identity Claims

Introduction	152
Theorising Identity	153
Self	154
Identity, the Self and Disability Studies	159
The Rejection of Impairment in Construction of Self-Identity	162
The Reconstruction of Normality in Constructions of Self-Identity	172
The Political Consequences of the	

Rejection of Impairment as an Identifier	174
The Incorporation of Impairment into Constructions of Self-Identity	177
Conclusion	182
 Chapter 7: Maintaining Identity	
Introduction	185
Experiencing Identity and Difference	186
Identity/Identification	189
Constructions of identity; identification as a disabled/non-disabled person	191
The Struggle for Identity	196
Reducing the Struggle and Affirming Identity	203
Challenges to Identity	206
Acceptance and Identity	212
Issues of Commonality	220
Conclusion	221
 Chapter 8: Impairment, Disablement and Identity	
Introduction	225
Summary	226
The Private Construction of Impairment	230
The Commonality of Disablement	232
The Personal Construction Identity	235
The Intersubjective Nature of Identity and Implications for the Political Construction of Disability	239
Concluding Remarks: Towards a New Political Construction of Disability	244
 References	256

Introduction

The first thing you need to do when writing about disability today is to clarify your terms, and this immediately gets you into the realm of social theory, since the most fundamental issue in the sociology of disability is a conceptual one (Abberley 1998;79).

To someone unaware of the debates going on both within the wider community of disabled people, and between and within disability studies and medical sociology, the notion of disability may be perceived as unproblematic and straightforward. People are disabled, and we know who disabled people are because of the way that they look or act; it is not, however, this simple. How disability is theorised, what the nature of disability is, and how it should be explained affects the social classification of disabled people which, as Oliver (1983, 1990) makes clear, has important implications both for the provision of services and the ability of disabled people to control their own lives. Bourdieu (1990) in his analysis of symbolic space and social power, shows how social classifications achieve this. First, he argues, they perform a diagnostic task, affirming what a person or a thing is. Second, via, for example, orders and prescriptions they make it clear what people have to do, given what they are and third, they describe what people have already done, as in authorised accounts such as medical reports. Social classifications organise our perceptions of the social world. The fact that these classifications are the product of such actions is soon forgotten and they acquire the appearance of the 'natural'. So, if for example disabled people are perceived as the victim of some tragic happening or accident, then they will be treated as such. This will

not only be reflected in the way that they are treated by others, who will create sympathetic biographies, but will also be translated into social policies (Oliver 1990).

Central to the social classification of disabled people is the issue of what causes disability. Thomas (1999) explains this eloquently ; the debate is between those who see an individual's impairment as the cause of their disability ('My disability is that I cannot walk' or 'He has cerebral palsy, therefore, he's disabled') and those who ascribe disability to society and reject any link between impairment and disablement ('It is society that disables me' or 'Your frame of mind is our disability'). The arguments revolve around whether disability is the result of a deficit in an individual or the product of social relations, or as Oliver (1996) terms it, individual versus social models of disability. Individual models of disability 'locate the 'problem' within the individual and....see the causes of this problem as stemming from the functional limitation or psychological losses which are assumed to arise from disability' (Oliver 1996;32). In contrast, social models locate the problem of disability squarely within society:

It is not individual limitations of whatever kind that are the cause of the problem but society's failure to provide appropriate services and adequately ensure the needs of disabled people are taken fully into account in its social organisation (Oliver 1996;32).

In Britain, this latter approach has been developed into what Oliver, in 1983, termed *the* social model of disability whilst the former, according to Oliver (1996) is typified by those who ascribe to, for example, the World Health Organisation's *International Classification of Impairment, Disease and Handicap* (Wood 1981).

The social model has much to recommend it as the onus for change is placed on society rather than on disabled people. Disabled people cease to be the object of intervention and are repositioned as subjects in their own lives (Shakespeare 1994). Disability is conceptualised as a form of social oppression, and disabled people become a distinct social group, in a similar fashion to the way black people, lesbians and gays have claimed through respective political movements. Consequently, it is not useful to separate various impairment groups - people with visual impairment, with physical impairment, with learning difficulties - as has been the practice of charities, schools and other agencies and organisations. This is an important insight into the collectivity of the disability experience. Organisations of disabled people have challenged traditional approaches to disability and a new and active socio-political movement has emerged, transforming disability into a major area of political concern (Barnes et al 2000).

However, this notion of a collectivity can obscure differences between disabled people, which may be about gender, ethnicity, sexuality, class, generation and impairment. It can also deny the individuality of disabled people, presenting disabled people as an homogenous group and presenting a notion of an essential unity of disabled people. It tells little of the actual experience of living with an impairment or of the personal experience of disablement, or of how disabled people feel about themselves. Consequently, a more structural, material analysis is favoured. There is little room to allow for the differences between disabled people, indeed to even acknowledge the presence of such differences could be seen as weakening the disability movement (French 1993;24), which, in the UK, has its theoretical framework in the social model. There is a danger that disabled people cease to be seen as individuals, the commonality of their experience is all important.

A new representation of disability and disabled people is emerging in the visual arts, in literature, in television and in film. In the photographic work of, for example, Gon Burman (in Davis 1997) gone are the images of disabled people as needy, as tragic, as brave and instead disabled people are presented as 'sexy', as desirable and as sensual. Lois Keith's (1994) anthology of writings and poems, *Mustn't Grumble*, presents accounts by disabled women which serve to counteract the popular view of disabled people in an honest and upfront way. In the BBC television series, *The Disabled Century*, David Heavey, the producer, has used narrative accounts of disabled people to show the oppression that they have faced throughout their lives. Importantly, in this series the medical and caring professions were presented not as saviours of disabled people, but as part of the oppressive forces that structure their lives. The mixed ability dance group CanDoCo have used dance to challenge stereotypical representations of disabled people.

All these forms of endeavour have the disabled person as the subject. Disabled people are not objectified and presented as part of what Darke (1998) has termed the normality genre, in which disabled characters appear so as to 'reinforce illusions of normality; a normality either exhibited in a film's non-impaired character or in the impaired characters rejection of their impaired self' (p184). So, for example, in Tom Shakespeare's documentary *Ivy's Genes*, his daughter is the subject of the film and her views, together with Shakespeare's own, provide a framework through which images of disabled people can be challenged.

However, whilst these moves are to be welcomed, they raise the question 'Who is this subject?'. In the same way that Hall (1990) questions who the emergent subject is in

'Third Cinemas', so the question becomes who are the disabled people that are so represented? Where do they come from and where do they speak from? As Hall writes:

Practices of representation always implicate the positions from which we speak or write – the positions of *enunciation*. What recent theories of enunciation suggest is that though we speak , so to say 'in our own name', of ourselves and from our own experience, nevertheless, who speaks and the subject who is spoken of are never identical, never exactly in the same place. Identity is not as transparent or as unproblematic as we think. (1990;222 italics in original)

There are vital and interesting things happening around disabled people. These cultural changes may also be reflected in changes at a personal and social level. These include disabled people's relationship with their body, their social interactions and their identity construction and these could form the basis of a truly embodied sociology, or social theory, of disability. This suggests an approach from a theoretical perspective that avoids the dangers of biological determinism found in much of the writings on disability that have emerged within mainstream medical sociology (as found in, for example, the work of Bury 1997) and the reductionism of social construction (as found in the social model). Such an analysis could form the basis of a more complete theoretical and political strategy (Shakespeare and Watson 1995a).

As a disabled person I have a personal commitment to the aims of disability studies and the disabled people's movement, and I am an active member of both these groups. This thesis is not an attack on the social model of disability. The social model has been, at both a personal and a political level, a useful tool. As an activist within an organisation of disabled people, which fully endorses and works within the social model, I have seen,

at first hand, the potency of the social model. Also, working in a Department of Nursing, and having, in the past, studied rehabilitation engineering and been the object of rehabilitation programmes I was aware, at a personal level, of the oppressive nature of much that is written about disabled people. Reading the literature that has emerged from disability studies was liberating, no longer was I a problem or a deviant case, the fault lay with society. Yet, despite this, perhaps, as we move into the twenty first century there is a need to move beyond the materialist analysis that has, until recently, been the dominant voice in disability studies. There is a need to develop a more embodied social theory which can reflect the diversity and fluidity of the disability experience. It is this that this thesis sets out to achieve. It does so by seeking and analysing the views of 28 people with a physical impairment around issues to do with embodiment, impairment, disablement, social interaction and identity and linking these to a range of theoretical considerations.

The Structure of the Thesis

The first chapter, *Theorising Disablement*, maps out current theoretical debates around disability. It draws mainly, though not exclusively, from British theorists. The chapter is subdivided into two main sections; disability as deviance and the conflict perspective. The first section concentrates on writings that have, in the main, emerged from mainstream medical sociology. It examines and offers a critique of how disability has been explained from the perspective of structural functionalism, symbolic interactionism, phenomenology and theories founded on biological difference. In the second section the social model of disability is explored in detail, including a brief look at its history and current thinking on the social model. It concludes with a critique of the social model, which sets the scene for the next chapter.

In the second chapter, *Theorising Impairment*, the importance of the body and embodiment for disability studies is discussed. It first looks at how the body has been theorised within disability studies, it then moves on to examine how post-structural and postmodern theorists have written about impairment and finally explores phenomenological writings on the body. In this final section, the issue of embodiment is addressed using, in particular, the anthropological writings of Csordas (1990, 1993). This section sets an agenda for the study of the embodied experience of impairment, arguing for an analysis of the taken-for-grantedness of the body.

The third chapter, *Researching Disablement*, sets out the theory that underpins the empirical work in this thesis. It starts with a brief discussion on the place of experience in disability research and explores the notion of what Oliver (1992) terms, emancipatory research. The next section explores the issue of experience itself and the theoretical debates about whether experience can ever be captured through empirical work. It then moves on to explore reliability, validity and objectivity in research. The chapter ends with a description of the research method, in-depth interviews, employed in this thesis. The recruitment of the informants, the structure of the interviews and the analytical method are outlined.

The next four chapters all chapters involve exploration and analysis of the data generated by the study. Chapter four, *Experiencing Impairment*, analysis the informants' accounts of discussions of their body, thus exploring their relationship with their body. These data show how, for some of the informants, their impairment has become part of their embodied sense of being. It does not represent what Gerhardt (1989) terms, trouble. However, the impairment can be brought to the attention of these informants depending on context. This awareness of the body can be brought about through change, through

environmental barriers or through interaction. This forms the next section of the chapter. For some of the informants, their impairment and their body was never silent. The next section explores how the participants related to their body and the care they took of it. The final section is based around data in which the participants describe how their relationship to their body was affected by their emotions and feelings.

In chapter five, *Daily denials: the routinisation of oppression and resistance*, the research participant's accounts of their daily interactions are documented. The chapter starts with a brief review of the importance of social interaction in our daily lives, drawing particularly on the work of Goffman. The informants' accounts clearly show that the one thing that all the participants have in common is a shared experience of oppression, although how that oppression is interpreted varies between individuals. The analysis shows how, through social interaction, the informants are made aware of how society views them. They are made the centre of unwanted attention: The informants describe how non-disabled people are often embarrassed by their very presence, how they are denied a sexuality and how they are depersonalised. The chapter also documents their resistance to these challenges.

Chapter six, *Identity Claims*, explores the research participants' accounts of self-identity. Many of the informants reject an identity based on the label disabled. That is, they do not see themselves as disabled, preferring to emphasise other parts of their lives in their claim to an identity. Disability, or the presence of an impairment does not, according to these informants, mark them out as different. The data show how some of the informants reconstruct normality, directly challenging the concept that is used by others to mark them out as different; normal is as normal is. The political consequences of this are

explored. Importantly, there were also a small number of the informants who self-identified as disabled and the views of these informants are examined.

All of these constructions of identity are held in spite of, and maybe in some cases because of, the views of the society in which they live, as shown in the preceding chapter. How the informants maintain their identity and what they seem to base their identity construction on, form the basis of chapter seven, *Maintaining Identity*. The analysis of the data in this chapter describes how some of the informants challenge other's views of their identity through the image they present to others whilst others accept the identity of a disabled person. The struggles they endure to claim their identity and how that struggle can be reduced are also explored so too are the issues of acceptance, the commonality of disablement and shared understandings between disabled people.

The final chapter, *Impairment, Disablement and Identity*, discusses the implications of the preceding analysis. After providing a brief summary of the thesis, this chapter examines the fact that the body is only made relevant to disabled people when placed in a situation that reminds them that they have an impairment. This forms the central theme of the first section of this discussion. The chapter then moves on to explore one of the major ways in which the body is made apparent to disabled people; the common, shared experiences of disablement. It is suggested that the experiences of impairment and disablement are so inter-linked that theoretical models that attempt to separate the two cannot fully capture the experiences of being a disabled person. The next two sections examine the identity claims and the formation of these identities by the informants and, in particular, what the implications of these are for the disabled people's movement. The final section puts forward a new approach to the study of disablement based on the data that have emerged from this study and the work of Honneth (1995).

The discussion ends by proposing a new, tripartite, approach to the study of disability. First, disablement should be explored at the interpersonal level. The social model, with its emphasis on material relations, distances disabled people by denying the importance of their own private experiences. Impairment should not be ignored, neither should it be separated from disablement; both are linked. Second, as disabling social relations are everywhere, disability studies and the disabled people's movement should continue its work on challenging meta-narratives. However, these challenges must be portrayed as situated and historically contingent and presented in a language so as to engage with disabled people. A bridge must be developed between the impersonal aspirations of such challenges to meta-narratives and disabled people's private experiences. Third, academics and activists should continue to present detailed documentaries and ethnographies of the lives of disabled people so as to present a picture of the realities of being a disabled person in the 21st Century. Through these, solidarities will emerge both between disabled people and with people who are not disabled; disability will be seen not as the product of an individual trait, the impairment, nor as simply a social product, but as a fluid multiplicity which is subject to complex structural and interactional factors.

Chapter One

Theorising disability

Introduction

This chapter focuses on the meanings of disability in both medical sociology and in disability studies. It explores how disability is conceptualised within these two paradigms and characterises the ongoing debates both within and between them. It examines how the representation of disability attaches meaning to the concept disability, and therefore influences how the subject is theorised and studied.

Albrecht (1993) provides a useful distinction between the various approaches to the social classification of disability and suggests that there are two dominant paradigms in the analysis of disability, namely:

- The deviance perspective, in which disabled people are portrayed as departing from the societal norms
- The conflict perspective, in which disabled people are considered members of a minority group (p71)

This simple taxonomy provides the framework for this chapter. The first section explores writings on disability which draw on the deviance perspective. This includes structural functionalist perspectives, symbolic interactionism and labelling theory, phenomenological accounts and the World Health Organisation's (WHO) classificatory

schema. The second section draws primarily on the writings from disability studies scholars and examines the social model of disability.

Disability as deviance

There are two main models of disability underpinning the theorising of disability as deviance. First are those accounts located within a sociology of deviance and second are those which locate the deviance in the body; what Bury (1996, 1997) terms the 'socio-medical model of disability'. These are examined in turn.

Disability as Societal Deviance

Whilst the sociology of deviance is largely an American perspective its influence on medical sociology, particularly in the exploration of chronic illness and impairment are clear (see for example Gerhardt 1989). This school of thought derives its theoretical base from structural functionalism and symbolic interaction theory and phenomenology.

Structural functionalist perspectives

Structural functionalism dominated sociology in America in the 1940's and 1950's. Gerhardt (1989) has argued that medical sociology owes its origins to the founder of structural functionalism, Talcott Parsons. For Parsons, social relations take place within a consensualist society. Order and harmony are preserved, provided individuals act within certain predefined roles. Illness results in physical disability or incapacity which act to prevent an individual from fulfilling his or her role in society. People who have an impairment or illness are seen as involuntarily deviant, as opposed to criminals whose deviancy is seen as voluntary, but, regardless of the involuntary nature of the condition they must fulfil certain roles if they are to escape censure from society. They must try to get well and put themselves in the hands of their doctor or other medical professional, fulfilling their sick role. By doing this they are absolved from societal obligations and

culpability for their condition is removed (Parsons 1951).

However, when applied to disabled people there are many problems with Parson's analysis. Not only does it fail to examine conflict (Freidson 1970) but, for many people with stable impairments such as cerebral palsy, the impairment can cease to be a medical problem. In addition, as Albrecht (1993) points out, impairments that are transitory lend themselves better to Parson's sick role whilst those which are chronic, and from which recovery is unlikely, do not allow a return to the full pre-illness role and Parson's analysis is unworkable:

Impairments that are acute and transitory in nature lend themselves more readily to analysis through the sick role conceptualisation. Many other impairments, however, are permanent or chronic in nature, so complete recovery with a full return to health and pre-illness roles is impossible (1993;72)

Whilst this approach has largely been abandoned in writings on illness, it is still occasionally evident when disability is discussed. For example, in Sarah Nettleton's (1995) text book on medical sociology, her explanation of the sick role is included in the chapter on disability and chronic illness. Further, disability is still often lumped with chronic illness in medical sociology. Bury (1996) argues that there is little real difference between the two. Many impairments are changeable, dynamic and episodic. Few have no medical implications whatsoever. The majority of disabled people do not have stable, congenital impairments (such as blindness or deafness) or sudden traumatic lesions (such as spinal cord injury, SCI), but instead have rheumatism or cardio-vascular disease, or other chronic degenerative conditions mainly associated with ageing. Even conditions such as polio and SCI are not 'once-for-all' changes without subsequent

variations: post-polio syndrome is now well documented, and people with SCI have to manage urinary-tract-infections, pressure sores and other problems..

Symbolic interactionism and labelling theory

Symbolic interaction theory first emerged in America at the turn of the last century and heralded an interest in the concept of self and identity within sociology. Charles H Cooley, John Dewey, George Herbert Mead and William Thomas, the most influential of the early interactionists, broke with the tradition prevalent in American sociology at the time of separating the self from society,. They conceptualised the individual and society as inseparable and interdependent units. Individuals, according to this philosophy, were reflective and interactive beings possessing selves. Consciousness and minds were no longer seen as “givens,” the result of a biological inheritance, but the outcome of social interaction. Similarly, objects became the product of symbolic interaction.

..an object is anything that can be indicated or referred to. The nature of an object - of any and every object - consists of the meaning that it has for the person for whom it is an object.....The meaning of an object arises fundamentally out of the way they are defined to him by others with whom he interacts. (Blumer 1969:11)

Meaning and status ceased to be seen as fixed attributes but were subject to local and historical transformations and contingencies.

[Symbolic interactionism] does not regard meaning as emanating from the intrinsic make-up of the thing, nor does it see meaning as arising through psychological elements between people. The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to

the thing. Their actions operate to define the thing for the person. Thus symbolic interactionism sees meanings as social products formed through activities of people interacting. (Blumer 1969;5)

The study of deviance was central to the work of symbolic interactionists,: 'Social action falls into two categories: conformity marked by adherence to the structure, and deviance marked by departure from it' (Blumer 1969:74). Through the study of deviance, it was claimed, a better understanding of the social order emerged, as did an understanding of the way deviant patterns and lifestyles were themselves organised. For symbolic interactionists, disability is clearly presented as a form of deviance. For example, Freidson writes:

By definition then, a person said to be handicapped is so defined because he deviates from what he himself or others believe to be normal or appropriate. In this sense the concept of *deviance* is central to the rehabilitation activity (1968;72)

This approach has dominated much of the writings on disability and chronic illness (Gerhardt 1989). It includes work by, for example, Strauss and Glaser (1975), Strauss and Corbin (1991), Schneider and Conrad (1983) Scrambler (1989), Freidson (1966, 1970), Davis (1973), Goffman (1968)¹ and Charmaz (1983). However, much of this work neglects conditions of inequality, powerlessness and violence, focussing on the individual rather than the wider society (Liazos 1972). For example, Charmaz (1983) clearly links the presence of a chronic illness with a loss of self: 'As they suffer losses of self from the

consequences of chronic illness and experience diminished control over their lives and their futures, affected individuals not only lose self-esteem, but even self identity. Hence suffering such losses results in a diminished self' (1983; 169). Whilst clearly providing an account of the impact of chronic illness on people's sense of identity and its influence on daily living and social relationships she fails to examine cultural meanings ascribed to impairments or chronic conditions. It fails to address why disabled people tend to be excluded. It presents disabled people as 'vulnerable' and fails to explore fully the cultural context within which the experience of social isolation, segregation, and poor self-image are lived.

Work in this paradigm then, focuses on the difficulties that chronic conditions raise in interpersonal relationships and the way that individuals negotiate their way through these difficulties. As Strauss and Corbin write:

When a severe chronic illness comes crashing into someone's life, it cannot help but separate the person of the present from the person of the past and affect or even shatter any images of the self held for the future. Unless the illness is mild or its effect on activity is relatively negligible, who I was in the past and hoped to be in the future is rendered discontinuous with who I am in the present. New conceptions of who I am and what I am – past present and future – must arise out of what remains. (1991;341)

Management problems are at the forefront of much of the analysis; the emphasis is on the process of 'normalisation', and the tactics employed by individuals in 'symptom control':

¹ The work of Goffman is discussed in detail in the chapter 5

The chief business of a chronically ill person is not just to stay alive or keep his symptoms under control, but to live as normally as possible despite his (sic) symptoms and his disease. How normal he can make his life (and that of his family) depends not only on the social arrangements he and they can make, but on just how intrusive are his symptoms, his regimes, and the knowledge that others have of his disease and of its fatal potential. If none is very obtrusive on interactional or social relations, then the tactics for keeping things normal need not be especially ingenious or elaborate. But when regimen, symptom or knowledge of the disease turns out to be obtrusive, then the sick person has to work very hard at creating some sense of semblance of normal life for himself (Strauss and Glaser 1975; 58)

Disability or impairment are presented as *master status*, one that limits an individual's ability to access social roles, so that they are reduced to adopting a range of subsidiary roles (Gerhardt 1989).

The approach in much of this writing appears judgmental and normative. The very term 'deviance' connotes a moral judgement and the often flowery language that they use leaves little doubt about the author's feelings. For example, Kleinman (1988) uses terms such as 'pathetic' (p.xi), 'stoic' (p.39) and 'denial' (p.39) as he describes the people in his study. They, as Lofland puts it, 'participate knowingly or not, intentionally or not in the reinforcement of popular ideology.' (1969;10).

Labelling theory, although coming from the same stable as symbolic interactionists, moves attention from the deviant to the ascription of deviance. In other words the focus

is on society rather than the individual. The writings of Edwin Lemert (1951, 1967) and his notions of primary and secondary deviation have been central to this field. Primary deviation is defined as the act or attribute; whilst secondary deviation is the deviant behaviour as defence, attack or adaptation to the problems created by the reaction of society to the primary deviation. So Lemert writes:

Although physical handicaps partially restrict opportunities for achievement, the more critically operating limits come from an overlay of interpersonal and formal social barriers founded on cultural stereotypes about physical deficits. (1967; 16)

Although Lemert discusses disability throughout his texts, a classic example of labelling theory as applied to disability is found in Robert Scott's *The Making of Blind Men* (1969). He focuses on the institutions and agencies which are involved in socialising blind people into the social role defined for them. Blindness, he suggests, holds an imputed set of role values: 'Helplessness, dependency, melancholy, docility, gravity of inner thought, aestheticism - these are the things that common sense tells us to expect from the blind' (p4). Once a person enters the blind role, institutionalised processes force people to adopt certain behaviours². These institutions serve two purposes; first, they help the blind person become a blind person and, second, they allow the rest of society to dump those deemed unwanted into a place where they feel some good is being done to them. Scott, by problematising the category of 'blindness' itself, argues that those who are technically defined as blind become socially blind through social labelling. Unlike the work cited above, Scott's analysis is embedded within cultural meaning. Society creates the category 'blindness' and through attaching meaning to this category, the 'blind person' emerges.

Similarly Mike Kelly's (1991, 1992a, 1992b, 1994a, 1994b, 1996) work on ulcerative colitis takes into account cultural stereotypes. He explores the effect of colitis and subsequent radical abdominal surgery on the self and public identity construction. He unveils the way in which everyday interaction has been 'spoiled'. Kelly, unlike the theorists mentioned above, warns against a simplistic analysis based on role theory or deviance:

...this kind of thinking leads to some unhelpful stereotypical accounts of illness or disability. The person is the role. In these cases the person becomes an ileostomist or an ulcerative colic.....the person becomes the role and the role becomes the person loaded with sociological meaning. (1996;90)

He argues that people's interaction with others draws on both their own experiences of living with the condition and the cultural meanings ascribed to their condition. These two conjoin, and both are significant. Individuals recognise that they are not just a condition, but that cultural representations of the condition 'form a strong component of anticipated responses from others in the negotiation of identity and presentation of self' (1996;91).

Michael Bury, perhaps one of the most influential writers in this field in the UK, in his two major reviews of the sociology of chronic illness and impairment (1991, 1997) identifies three main themes that have emerged through medical sociological accounts of disability:

First, is the *biographical disruption* brought about by such illnesses and the initial

attempts to deal with the uncertainty it brings; second, is the impact of treatment on everyday life, where this is relevant; and third is the long term *adaptation and management* of illness and disability which is undertaken as people respond and try to reconstruct normal life. (1997;123 italics in original)

Biographical disruption, as described by Bury (1982, 1991, 1997), is a term used to explain the impact that a chronic condition can have on an individual's expectations and achievements. The presence of a chronic condition and its effect on activity and independence, Bury contends, shatters and disrupts the social and cultural fabric of that person's life, altering their life situation and social relationships (1997;124). This changes over time. At the onset of the condition, it is the *consequences* and *significance* of that condition that are paramount. That is, it is the impact that it has on a person's everyday roles and relationships and the symbolic and cultural meanings which surround different sorts of illnesses and impairments. Over time, biographical disruption can be mitigated through individuals constructing an explanation for their condition and establishing its legitimacy. Bury, drawing on the work of Gareth Williams (1984, 1986), suggests that 'a form of "narrative reconstruction" of events leading up to and through the illness' is established 'in order to reduce its threat to the everyday meanings that had hitherto prevailed' (1997; 125). Legitimacy is achieved through an individual acknowledging that their lifestyle has been changed as a consequence of acquiring the chronic condition and that its place is established within an altered daily life and incorporated into social interactions. An altered identity is constituted and the public and private life of the individual organised so as to reduce the disruptive effects of the chronic condition. Through the twin processes of legitimisation and explanation people with a chronic condition are able to create a meaningful story about their condition. However, as Simon Williams makes clear, this sense of new self is very different and implicitly

weaker or slightly less worthy than the previous self:

....individuals do, none the less, struggle, sometimes heroically, and against all odds, to effect something of a realignment between mind and body, self and society. Here, a sort of 'negotiated settlement' (Williams 1993) occurs which, although never quite able to return the individual to their former embodied self, nonetheless attempts an approximation to it. (1996;)

Whilst the notion of struggle seems to accord with common-sense expectations, it is the tone of this statement that is problematic. If the same had been written about, for example, a young man discovering he was gay, would 'heroic struggle' be the type of language used?

The impact of treatment on everyday life refers, according to Bury, to the way in which individuals come 'to grips with treatment regimes and medical interventions, and with the bureaucracies from which they emanate' (1997;126). It involves the person gaining an understanding of the official diagnosis and labelling, searching for information on their condition, making sense of this and incorporating it into their restructured social world, embarking on what Robinson (1988) terms the 'medical merry-go-round.' It is about learning how to manage health requirements and discriminating between 'helpful' and 'unhelpful' sources of knowledge, advice and expertise (Dingwall 1976). Kelly's earlier work on colitis (1992a), for example, explores how those with the condition have to be constantly aware of their body, self-regulating and surveying, having to learn how to keep things hidden from others. This work, by focussing on the impact of treatment and care, presents an image of disabled people as being in need of care. This serves to reinforce the dominant view of disability as a medical rather than social problem, with

the emphasis on individual adaptation to impairment.

Adaptation and management of illness and disability is about how individuals cope with an impairment, how they develop a strategy and a style to achieve 'the best quality of life possible' (Bury 1997;129). It is about the way that individuals achieve a 'normal' life, as Bury describes it, despite the presence of an impairment. The term *coping*, as Bury (1991, 1997) acknowledges, implies a moral framework against which an individuals ability to cope is judged. However, following Radley (1994), Bury argues that coping should be seen as a means of determining the ways in which individuals maintain or recover a sense of self-worth. It is about the emotional and cognitive mechanisms that people with impairment employ in adaptation to their new life situation, it involves 'maintaining a sense of value and meaning in life, in spite of symptoms and their effects' (Bury 1991; 461). This is achieved in a number of ways. Kellaher (1988), for example, suggests that coping involves 'bracketing off' the impact of the impairment, treating the illness as 'normal' so as to reduce its impact. Scrambler (1989) writes about how people with epilepsy have to come to terms with and manage their status.

For Kelly (1992b), coping with a chronic condition operates at four levels: (i) the technical and practical management of the condition (for example learning how to use catheters, colostomy bags or medication), (ii) the intrasubjective management of thoughts and feelings, of pain and of emotion, about the impact of the condition, (iii) the management of interpersonal relationships, including the renegotiation of long-term relationships and the presentation of the self and, (iv) the intersubjective level of creating meaning, interpreting and making sense of the condition.

Despite claims by Bury and others that the notion of 'coping' is not judgmental, the very

nature of the approach implies that there is something wrong with the individual in the first place. Disabled people or people with a chronic condition are presented as essentially different from their non-disabled peers and that they have lost their sense of worth or that this is challenged because of the presence of impairment. Their sense of worth has to be worked on and they have to learn how to cope with this and, further, this ability to cope is judged against a moral backdrop of success or non-success. Success and non-success are, themselves, of course, normative constructions.

The *strategies* that disabled people adopt is the second element of what Bury (1991, 1997) describes as the adaptation process. This refers to the actions or practices people adopt in the face of chronic illness or impairment rather than to meanings or attitudes. Through successful actions the individual learns how to maintain hope and a sense of the future. It is about how people 'get around' in everyday life. As Simon Williams explains:

....the chronically ill are faced with two contradictory imperatives....namely, the *inner physiological imperative* of pain and physical disability, and the *outer world of activity* involving the maintenance of what is perceived to be as near normal an existence as possible. Faced with these two imperatives individuals are left to 'juggle the hope of relief against the dread of progression', to normalise in the face of uncertainty and to balance options through a variety of strategies such as 'covering up', 'keeping up', 'pacing', and 'justifying inaction'.this involves a process of 'spiral renormalisation' into lower and lower expectations and the development of new norms of action as the disease progresses. (1996; 35-36)

Style refers to the way in which people respond to and manage their condition, the

performance that people living with impairments undertake (Bury 1997;132). It is about finding an appropriate style of living so as to minimise the impact of the condition and maximise participation in society (Radley 1994).

Whilst symbolic interactionist approaches have provided useful avenues of research the method does raise a number of issues and it is to these that this chapter now turns. They allow an exploration of the consequences of being a disabled person in practical situations. The positions of disabled people are taken seriously and credence is given to the views of disabled people so that they can themselves become the best guide to their own position. This allows the emergence of a variety of perspectives and patterns of social life can be uncovered, as can the world that disabled people inhabit. Through such an analyses the world which constrains and enables disabled people can be investigated through the embodied actions of disabled people themselves and not abstract, philosophical speculation. However, whilst by definition, research and theory that emerge from the interactionist paradigm place disability as social in origin, the analysis raises many problems. In spite of the acknowledgement of conditions of inequality, powerlessness and violence, (see for example Bury (1997; 118-119)) they are rarely placed at the centre of the research or analysis (G. Williams 1996). Even in the work which purports to incorporate or acknowledge wider social issues the focus is still very much on the individual. The explicitly normative nature at the heart of much of this research is also deeply problematic. Having an impairment, it appears, separates the individual from the rest of society and their impairment becomes their defining characteristic. Much of the analysis seems voyeuristic, the disabled person is objectified as are their lives. Simon Williams (1996) writes about the vicissitudes of chronic illness, but seems to ignore the vicissitudes of daily life. We all face change throughout our lives; leaving school, getting a job, starting a relationship, ending a relationship, buying a

house, having children all challenge an individual's sense of worth and identity. All result in biographical disruption, impact on one's sense of self and require coping, strategy and style as one adapts to their consequences. Yet these are seen as normal, they are rarely used as defining characteristics of an individual (at least not in sociological texts). For disabled people it is different, as Carver and Rodda put it:

To be described as disabled, or even worse as one of the disabled, is....to be designated as belonging to a different and probably inferior order of beings”
(1978:4 in Oliver 1990)

Phenomenological accounts of disability

There has been a recent growth in the influence of phenomenology³ in writings on chronic illness and disability (Bendelow and Williams 1995, Charmaz 1991, Frank 1995, Good 1994, Monks and Frankenburg 1995, Murphy 1987, Sacks 1985, 1986). Conrad (1990; 1260) traces this growth to the emergence of an interest in the insider's perspective in symbolic interactionism. Increasingly writers from within that paradigm felt dissatisfaction with what were perceived as impersonal conceptualisations inherent in their work. As Good writes:

Research that attends only to semiotic structures or social processes seems to miss the essence of what gives illness its mystery and human suffering its potency.....illness itself, the object of medical knowledge, is socially and

³ In reviewing this literature it was often difficult to decide whether the work was phenomenological or interactionist. Some of the work included in this section some may feel is interactional whilst some of the work covered in the last section may be considered phenomenological.

culturally variant. An understanding of what this could mean, the development of a theoretical frame to account for findings of enormous variation in the course and prognosis of such profoundly debilitating diseases as schizophrenia, and the development of categories and methods for investigating how illness varies across cultures all require serious attention to what Arthur and Joan Klienman (1991) have recently called the 'ethnography of experience.' (Good 1994; 117-118)

It is beyond the scope of this chapter to fully explore the theoretical basis of phenomenology. Put crudely and simply, phenomenology is a descriptive science concerned with presenting a picture of the problems of being-in-the world and meaning. The point of departure is the notion that human actions are governed by subjective meaning and the aim of phenomenology is to interpret the action of individuals in the social world and the ways in which individuals give meaning to social phenomena. The writings of Husserl, Schutz and Merleau-Ponty have been influential in this area. Meanings are the subjective meanings of other individuals, there being no real world, only a world of abstractions. The world that we live in is created within our heads and sociological interest is limited to 'the world in so far as it is meaningful' (Craib 1992; 98). This world is the world of common, immediate, lived experience and through an exploration of 'space time and the world as we 'live' them' an attempt is made to gain 'a direct description of our experience as it is' (Merleau-Ponty 1962: vii). To explore this, an understanding of how the world is made meaningful is necessary. This is 'achieved through setting aside what we normally assume we know and tracing the process of coming to know it' (Craib 1992; 98). This is termed 'bracketing' or 'epoche'.

The Objective world, the world that exists for me and always will exist for me, the only world that ever can exist for me – this world with all its objects, I said,

derives its whole sense and its existential status, which it has from me, from me myself, from me as the transcendental ego, the ego who comes to the fore only with the transcendental-phenomenological epoche.

This concept of the transcendental and its correlate, the concept of the transcendent, must be derived exclusively from our philosophically meditative situation. The following should be noted in this connection: Just as the reduced Ego is not a piece of the world, so conversely, neither the world nor any worldly Object is a piece of my Ego, to be found in my conscious life as a really inherent part of it, as a complex of data of sensation or a complex of acts (Husserl 1970; 26 in Hindess 1977; 59).

In the phenomenological writings of Merleau-Ponty, it is through the body that Objects and the world are experienced. The body is the active agent in world construction. Perception is grounded in the experienced and experiencing body. The world and Objects as perceived through the body are the ground level for all knowledge as it is through the body that we gain access to the world and its objects (Merleau-Ponty 1962). Bodily being is experienced through language, through motions, through gesture. Importantly, Merleau-Ponty stresses the embedded nature of the relationship between the body and the senses. Sensation and perception cannot function independently of the body, neither should they be viewed as being 'cemented' on to the body, as a Cartesian reading of the body may suggest, but as fluctuating between the two (Nettleton and Watson 1998). This is the basis of embodiment as described by Merleau-Ponty⁴ (Turner 1992; 56)

This suggests that whilst all actions are embodied, embodiment is not always conscious. Many actions that are undertaken are performed without conscious reflection on the embodied nature of that action. For example, Schutz (1970) writes that we only become aware of actions if they are novel or occur in a novel situation. In such circumstances we are forced to analyse the situation, consider different interpretations, examine recipes for action and pick what is the most appropriate and performable. Conversely, in routine activities there is no need for interpretation, they can be performed automatically.

Leder (1990) takes this analysis further, in arguing that, in most actions, the body itself is a 'taken for granted', an 'absent presence':

While in one sense the body is the most abiding and inescapable presence in our lives, it is also essentially characterised by absence. That is, one's own body is rarely the thematic object of experience. When reading a book or lost in thought, my own bodily state may be the farthest from my awareness (1990;1).

Impairment, in this approach, causes the body to *dys*-appear, that is people become aware of their bodies because it is in a *dys*-functional state: 'The body appears as a thematic focus of attention, but precisely in a *dys*-state – *dys* is from the Greek prefix signalling bad, hard or ill and is found in English words such as dysfunctional' (Leder 1990; 84 *italics added*). It is through pain and disease, as Bendelow and Williams (1995) argue, that the body ceases to be absent and becomes present in an unfamiliar manner.

In a similar vein to that of the symbolic interactionists, many phenomenological accounts of disability place at the centre of their analysis the ways that people with an impairment

⁴ This is discussed in more detail in chapter 2

or a chronic condition seek to re-establish their place in the world after the onset of that condition (Williams G 1996). However, the focus shifts from an individual's interaction with their social and material world to their 'self' and 'body', and to how impairments are made meaningful and how social worlds are constituted through meaning. So Bendelow and Williams write:

It is through narrative and the theodicies of illness and pain that people attempt to understand and locate the meaning of their suffering and to effect a realignment between body, self and society. (1995; 156)

The basic premise of many of the phenomenological accounts of disability, is that the presence of an impairment diminishes a person's 'moral status' (Gerhardt p.190). As Vosey, in one of the first major British texts to examine disability from a phenomenological perspective, argues:

When moral character is *not* imputed, the entity concerned is not regarded as a person. Since the ascription of intellectual character is a necessary condition of that of moral character, and to the extent that the ascription of moral character is influenced by physical characteristics, then the disabled individual may not be regarded as a person. (1975; 32)

The presence of an impairment challenges an individual's sense of being in the world. To meet these challenges, 'normalisation' strategies have to be implemented. Impairment questions the taken for granted nature of everyday existence. Good (1994; 124-126), utilising Schutz's (1971) framework from his essay '*On Multiple Realities*', describes how chronic pain can undermine a person's sense of control and agency,

alienate people from their everyday world and others, disrupt a sense of time, distract, subvert lifegoals and bring to the fore a notion of vulnerability and mortality. These breaches of the taken for granted constitute 'trouble' (Gerhardt 1989). The body can no longer be trusted and 'the automatic expectation of a stable and predictable relationship between a person and their body can no longer be sustained' (Dingwall 1976; 98).

Phenomenological accounts of disability provide a useful corrective to the interactionist perspectives discussed earlier. By stressing the embodied nature of perception they go some way to meeting the challenges of Kelly and Field (1995, 1996) and Williams S (1996) who argue that much of medical sociology has failed to acknowledge the embodied nature of the experience of chronic illness and impairment. This embodied element in phenomenological writings is elaborated in the next chapter. However, phenomenology is, as Turner (1996; 78) points out, an individualistic account presented from the point of view of the subject and is 'devoid of historical and sociological content'. The emphasis on description precludes an analysis of existence; there is no attempt to explore the 'real' world in which disabled people operate, how the structures in this world may hinder or enable their practices, their identity and their sense of citizenship. The work of Bill Hughes and Kevin Patterson (1997, 1999) in their attempt to construct a sociology or phenomenology of impairment and that of Elizabeth Grosz (1994) go some way to meeting these criticisms. This work is also discussed in the next chapter.

Disability as Bodily Deviance: The socio-medical model of disability

The socio-medical model of disability grew out of the recognition of a need for financial services for disabled people in the late 50's and 60's. It is not about the *meaning* of disability or the experiences of living with an impairment or chronic condition as outlined

above. The Harris survey (1971) which was published after research by the Office of Population, Census and Surveys (OPCS) carried out in the late 60's, was the first attempt to measure the extent of impairment in the UK. The WHO, under the directorship of Phillip Wood further refined this work and produced what is known as the WHO *International Classification of Impairment, Disability and Handicap*⁵. This classificatory scheme aimed to detail the consequences of disease and resulted in a tripartite distinction:

Impairment (I) : Concerned with abnormalities of the body structure and appearance and with organ system function, resulting from any cause; in principle impairments represent impairments at the organ level.

Disabilities (D): Reflecting the consequences of impairment in terms of functional performance and activity by the individual, disabilities thus represent disturbances at the level of the person.

Handicap (H): Concerned with the disadvantages experienced by the individuals as a result of impairments and disabilities; handicaps thus reflect interaction with and adaption to the individual's surroundings. (Wood 1981;14)

The intention of the WHO approach was to shift the definition from the disease based classificatory system of the *International Classification of Disease* (WHO 1976) to a socio-medical model. Impairment and disability, under this code resemble that of the ICD in that they are hierarchical and exhaustive. Impairments are conceived as a threshold

⁵ Whilst I could be accused of stretching the point in including the ICIDH in a section on deviance, the schema is, at its heart, evaluative. It implies that disabled people can be differentiated from non-disabled people on the grounds of their impairment and their ability to perform tasks.

phenomena, all that is involved in this classification is whether an impairment is present. Disabilities are viewed as an individuals failure to accomplish tasks. Handicap is different from all other ICD related classifications. It is not classified in terms of the individual, but in the terms of the situations in which individuals find themselves.. The schema is restricted to what are seen as the key social roles of orientation, physical independence, mobility, occupation, social integration and economic self-sufficiency. This serves to place disabled people at a disadvantage in relation to their peers when compared with societal norms

Bury (1979, 1996, 1997) argues that this model, whilst not without its problems, has been a useful tool in assessing the social needs of disabled people. The emphasis placed on material and social needs and their articulation with health needs has enabled, he suggests, a more nuanced understanding of the problems faced by disabled people to emerge. For example Jean Martin's OPCS survey commissioned in 1984 (Martin et al 1988) and others carried out between 1985 and 1988 'inform[ed] a review of the disability field, and pave[d] the way for such benefits to be based on a more systematic appreciation of the relational character of disability'. (Bury 1996;21)

Oliver (1990, 1996a,1996b) has been very critical of this work. He claims that far from creating a socio-medical model, the WHO classification is still rooted in the medical classifications of disease-disability-handicap. It links impairment with abnormality, disability with an inability to perform a task considered normal and handicap with the failure of an individual to perform a normal social role (1990;4). It completely ignores the issue of what normality actually is, and, importantly for an international classification scheme, fails to address the influence of sub-culture, gender or ethnicity on the concept of normality, focussing instead on the performative aspects of impairment. For example,

Ingstad and Reynolds-White (1995), in their recent collection of essays on Disability and Culture argue that the ICIDH taxonomy, by giving primacy to biomedical classifications, produces a universalising approach which excludes cultural determinants of disability. They cite the example of the Kel Tamasheq, a tribe in Kenya, who identify a variety of “faults,” including deafness, protruding naval, absent mindedness, illegitimate birth and flabby or small buttocks. These “faults” can prevent an individual from playing a full role in society. Whilst the WHO classification scheme does have a very extensive list of impairments (which is far more detailed than that of disabilities which are in turn more numerous than that of handicap) most of these are not in the WHO taxonomy. The WHO list, concentrating as it does on “organic” problems, does not recognise social problems.

The Conflict Perspective: The Social Model of Disability

The work of Mike Oliver (1983, 1990, 1996) has been most influential in the development of an understanding of disability from a conflict perspective and in the articulation of the social model. His work develops the ideas of disability activists who, in the 1970s, challenged understandings of disability, sought to dislodge the association of disability with mental or physical incapacity, and looked at the wider cultural construction of disabled people. The most influential of these organisations, in the UK, was the Union of the Physically Impaired Against Segregation (UPIAS)⁶. UPIAS were responsible, as Oliver (1983, 1996) makes clear for sowing the seeds of what was later termed the social model of disability in their groundbreaking manifesto *The Fundamental Principles of Disability* (1976). In this document UPIAS clearly locate the cause of disability in society:

⁶ For a history of UPIAS see Campbell and Oliver (1996)

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called "disability" of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or part of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities. Physical disability is therefore a particular form of social oppression. (UPIAS 1976:3-4)

Unlike the tripartite schema of the ICIDH, in this model any connection between impairment and disability is rejected. The model does not challenge the medical definition of impairment, but the definition of disability is radically different:

Impairment : Lacking all or part of a limb, or having a defective limb, organism or mechanism of the body.

Disability : The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (UPIAS 1976:3-4)

By locating disability in society it is not possible to reduce the cause of disability to the individual or to the biological. It shifts the focus away from the individual to disabling barriers and attitudes, as Vic Finkelstein writes:

Once barriers to the reintegration of people with physical impairments are removed the disability itself is eliminated. The requirements are for changes to society, material changes to the environment, changes in environmental control systems, changes in social roles, and changes in attitudes by people in the community as a whole. The focus is decisively shifted to the source of the problem – the society in which disability is created. (1980; 33)

It could be argued that Oliver's work, together with that of Finkelstein (1980, 1981) and Barnes (1991) have given academic credibility to the social model. Oliver's influential monograph, *The Politics of Disablement*, published in 1990 provides perhaps the clearest theoretical understanding of this approach to disability. His work draws on, for example, Comte, Marx, Gramsci and Weber. His analysis is a materialist analysis which produces a perspective which affords primacy to power relations, in which the cause of disability is placed firmly in societal structures.

Oliver used both the *Fundamental Principles* and the work of Finkelstein (1980) in formulating the social model. The basic tenet of the *Fundamental Principles* lie at the heart of the social model, but the definition has been broadened to accommodate all impairments and now forms the basis of the definition used by many organisations of disabled people such as Disabled People International (Dreidger 1989) and the British Council of Disabled People (Barnes 1997).

The social model is a structural analysis, based on the notion of disabled people as an oppressed minority group, and disablement as a collective experience. It distinguishes between the impairments that people have and the oppression which they experience and defines disability as the social oppression not the form of impairment. Disability is seen as a social construction, or as Oliver (1990) phrases it, a social creation.

Earlier, Finkelstein (1980) had linked disablement with the development of western capitalist society. He argued that through the creation of new productive technology and the advance of modern hospital based medicine (p10) disabled people were no longer able to be part of the work force and institutions emerged which segregated disabled people from the rest of society. Whilst this is an oversimplification of history, it should not be read literally but heuristically. It could be argued that what Finkelstein was attempting to show was how disability was the product of society and not the result of impairment, and whilst his argument is easy to refute through historical evidence on the position of disabled people in pre-industrial revolution Britain, it is his general theme that is important⁷.

⁷ There are numerous references in historical texts which show that the exclusion of disabled people is not a product of capitalism. For example, St Gregory of Nysee writing in the fourth century describes the lives of people with leprosy in the following manner:

They have no friends but each other, united as they are in misery; that which makes them despised of others unites them in a close bond among themselves, repulsed on all sides, they become in their union a people in themselves...Are they not excluded from public assemblies and feast days, like murderers, parricides, fated to be perpetual exiles, and even more unhappy than these. For murderers are at least permitted to live with other men; these are driven away like enemies. They are denied the same roof, the same table, the same utensils with others. Moreover they are barred from the cleansing waters for public usage, and there is a fear that even the rivers may be inflicted with their malady." (in Brody 1974; 80)

Oliver's (1990) analysis provides a much more comprehensive account. His materialist understanding of disablement firmly links the oppression that disabled people face to both the material changes associated with capitalist development described by Finkelstein, but also to ideological changes. Disability is not, according to Oliver, 'defined or culturally produced solely in terms of its relationship to the mode of production' (1990;22). He argues that disability is culturally produced through the relationship between the mode of production and the central values of society. Capitalist society has resulted in an ideology of individualism, which, coupled with medicalisation and the development of rehabilitation, brought about profound changes in the way that people with impairments are seen and treated. Drawing on Marx, he states that:

The requirements of the capitalist economy were for individuals to sell their labour in a free market and this necessitated a break from collectivist notions of work as the product of family and group involvement (1990;44)

Through the development of wage labour, he contends, the notion of 'able-bodiedness' arose, and disabled people could no longer meet the demands placed on them as part of a workforce and so became controlled through exclusion (p47). Disability became medicalised, with the medical profession emerging as the controllers of disabled people.

Oliver also uses the work of Deborah Stone (1984) who, in her analysis of the development and character of the welfare state shows how, through the establishment of rationalisation and bureaucratic processes associated with capitalism, a concept of 'disability' emerged so as to control access to a state sponsored welfare system. Her work explores the meaning of disability for the state. Disability, for the state, has become what she terms an 'administrative category' (*ibid* p4) as society attempted to classify

those who must work and those who could not work,. She argues that disabled people are accorded 'privilege' and 'exemptions' from their obligations as citizens. This, as she writes, 'is meant in a very precise sense: the state accords special treatment to some people who are disabled. Disability accounts for a substantial amount of income redistribution, and in a much smaller measure, for the distribution of some fundamental privileges and duties of citizenship – the obligation to serve in the national defence, to obey the laws of the state and to honour financial agreements' (p4). She is also at pains to point out that there is a flip side to these privileges: disabled people do face social stigma and economic hardship, are segregated from society and are made to feel dependent. Her historical analysis also shows how the criteria used to determine eligibility to the category of a disabled person and the subsequent financial benefits that may accrue such a categorisation are open to local interpretation and are contingent on local factors. The recent debates in the UK around the issue of incapacity benefit and the Benefits Entitlement Project add weight to Stone's argument.

Oliver, however, goes further than Stone and suggests that far from disability being solely an 'administrative category', the ideologies of both individualism and medicalisation affect the individual experience of disability. In other words, the experience of disability is 'structured by the discursive practices which stem from these ideologies' (1990; 58). Thus, what Oliver terms, an 'hegemony of disability' (1990; 44) emerges. By employing the Gramscian concept of hegemony Oliver argues that these ideologies have become dominant and are part of the common sense view of disability as a 'personal tragedy'.

Oliver asserts the existence of a set of beliefs in British society which give coherence to this hegemony of disability. Norms are set and these norms are used to oppress disabled people:

The hegemony that defines disability in capitalist society is constituted by the organic ideology of individualism, the arbitrary ideologies of medicalisation underpinning medical intervention and personal tragedy theory underpinning much social policy. Incorporated also are ideologies related to concepts of normality, able-bodiedness and able-mindedness. (1990;44)

In his analysis, culture acts very much as structure, popular consciousness is manipulated by the medical profession and others who serve their own interests in presenting disabled people as tragic victims. That is, 'ordinary' people are one dimensional and lack the critical capacity to challenge the dominant powers in society.

Writings and research in this paradigm focus on the disabling environment - the physical and social barriers which exclude disabled people and render them powerless and voiceless. Colin Barnes (1991) provides, perhaps, the most comprehensive and cogent account of the discrimination faced by disabled people in the UK. He documents the barriers to equal participation and opportunity in education, health service provision, employment, housing, transport, the built environment, leisure and social activities. This work has been replicated in other studies. For example Hyde's (1996) work on employment, Thomas's (1997) work on parenthood, Barton's (1995) work on education, Harris et al's (1997) work on housing and Zarb and Oliver's (1993) work on ageing.

All of this work presents evidence of the systematic discrimination against disabled people. It is clear that disabled people are treated unequally in almost all aspects of their lives. This discrimination spans both the public and private spheres and challenges those who suggest that disability should be seen as an individual experience arising as a consequence of unfortunate personal circumstances; what Oliver terms the personal tragedy theory. Their arguments are very compelling. The social model repositions disabled people from the traditional position of 'object' or 'acted on' to one of 'subject' or 'actor' (Shakespeare 1994). It closely mirrors early second wave feminist arguments. Thus when feminism distinguishes sex and gender (Oakley, 1972), disability studies separates impairment and disability, the former physical and the latter social and cultural (Shakespeare and Watson 1995a).

The relatively straightforward reconstruction of disability, from the individual to the social, has proved to be a powerful tool in the mobilisation of a movement, and in political campaigns for change. At a political level, the social model has enabled the discussion of disability issues within a discourse of rights and citizenship, rather than one of personal inadequacy and professional competence. Put simply, it is no longer the individual that has the 'problem'. Further, this social re-location of disability reflected the numerous attempts to create more enabling environments and has provided the 'big idea' (Hasler, 1993) for a more concerted political assault on disabling barriers (Barnes, 1991). The new paradigm for disability studies challenged the medicalised division of disabled people into professionally controlled impairment groups and offered a new sense of commonality in the shared experience of resisting oppression (Abberley, 1987; Oliver, 1990; Finkelstein, 1993; Campbell and Oliver, 1996; Priestley, 1998).

There is no doubting the political potency of the social model. The strength of the

Disabled People's Movement in the UK is testimony to this. It is also rhetorically appealing but its exposure to extended debate and academic scrutiny has placed it under strain. These critiques have come from both within the disabled people's movement and from outside. It is these critiques of the social model that this chapter now examines. The sense of political commonality often associated with the social model has been contested as an over-simplification of the complexity and diversity in disabled people's lived experience. Bury (1996) and Pinder (1996) accuse the social model of producing an 'over-socialised' conceptualisation of the processes involved in producing disability. It is, they argue, relativist and reductionist. By reifying disabling environments, the social model runs the danger of presenting only a partial picture of the experiences of disability. This partial picture is as potentially damaging as the focus on 'bodies-to-be-rehabilitated' found in the medical model. The social model represents only a 'part of a much more complex multi-layered picture' (Pinder 1996;137). What is required, they suggest, is a working definition of disability linked to impairment.

Similarly, there are a number of disabled writers such as Abberley (1987), Crow (1992, 1996), French (1993), Hughes and Paterson, (1997, 1999), Morris (1991, 1989) Shakespeare and Watson (1995 a & b) and Thomas (1999) who argue that, in addition to focussing on disabling barriers, disability research must acknowledge, examine and document the personal experience of impairment. For example, Jenny Morris' very popular and influential book, *Pride Against Prejudice* (1991) blurred the distinction between impairment and disability in several ways: she discussed the role of impairment and personal experience in the lives of disabled people; she talked about cultural representation; and she used terminology inconsistently, sometimes talking about

‘disability’ when in strictly social model terms she was talking about impairment⁸. Crow, in an article first published in *Coalition* in 1992 and later in 1996 writes:

The social model works well on a large scale – it is succeeding in tackling discriminatory social structures and demonstrating our need for civil rights legislation. Where it currently lets us down is at the personal level – its capacity to include and represent fully the range of disabled individuals. (1996;57)

Most recently, Carol Thomas (1999) has developed a promising new materialist approach to disability which explores the role of what she calls ‘impairment effects’⁹.

Paul Abberley (1987) is one of the few materialist disability studies theorists to take account of the impairment. He makes a distinction between social identities which do not have a bodily dimension which causes limitation – such as gender, race and sexuality – and the example of disability, where the body is a problem:

While in the cases of sexual and racial oppression, biological difference serves only as a qualificatory condition of a wholly ideological oppression, for disabled people the biological difference albeit as I shall argue itself a consequence of social practices, is itself a part of the oppression. It is crucial that a theory of disability as oppression comes to grips with this real inferiority, since it forms a bedrock upon which justificatory oppressive theories are based and, psychologically, an immense impediment to the development of political consciousness amongst disabled people. (Abberley, 1987, 8)

⁸ The work of Morris and her emphasis on experience is discussed in more detail in chapter three

Abberley's strategy is to show that impairment often has social causes. He argues that work, war, poverty and other social processes generate impairment, and therefore that impairment is itself part of disabled people's social oppression. Yet this move, while unassailable in its political validity, is not analytically sustainable. It may be dubious to suggest, as he does, that gender, race and sexuality do not cause limitation and what does he mean by 'real inferiority' and on whose terms?. Further, whilst, it may account for those impairments which are socially caused, it cannot account for those impairments which are idiopathic, random, or just bad luck.

Shakespeare (1994) and Pinder (1995, 1996) have both criticised the social model for its failure to include culture, although they reach different conclusions. Shakespeare (1994) notes the paucity of writings from social model theorists on cultural imagery, arguing that this stems from the neglect of impairment; 'If the social model analysis seeks to ignore, rather than explore, the individual experiences of impairment (be it blindness, short stature or whatever), then it is unsurprising that it should also gloss over cultural representation of impairment, because to do otherwise would be to potentially undermine the argument' (p283-284). Drawing on the writings of Simone de Beauvoir, Victor Turner and Mary Douglas he examines the cultural representation of disabled people in terms of otherness, ideology, anomaly and liminality. His work, alongside that of Hevey (1992), Darke (1998) Davis (1995) and the edited collection of Ingstad and Whyte (1995), explores how contemporary cultural representations of impairment generate disabling representations of the impaired body. These disabling images are every bit as oppressive as environmental or other material barriers. Shakespeare argues that such imagery portrays a fear of impairment:

⁹ Thomas' work is explored in more detail in the next chapter.

People project their fear of death, their unease at their physicality and mortality, onto disabled people, who represent all these different aspects of human existence. Disabled people are scapegoats. It is not just that disabled people are different, expensive, inconvenient or odd; it is that they represent a threat – either as Douglas suggests to order, or, to the self-conception of western beings – who, since the Enlightenment, have tried to view themselves as perfectable, as all knowing, as God like. (1994; 298).

Whilst this analysis is useful, in that cultural constructions of and about the body can sustain particular views and social relations as Needham (1973 in Sheper Hughes and Lock 1987) documents in the case of right versus left handedness¹⁰, there is a danger that Shakespeare's work could be used to suggest that such feelings are in some way essential to the experiences of impairment. By his failure to examine the origins of such cultural representations, his work runs the risk of presenting disabled people as other as a natural fact, as found in the work of Pinder (1995, 1996).

Scheper-Hughes and Lock (1987) provide a useful corrective to this. They argue that as society has become increasingly 'healthist' and body-conscious, so the politically correct body has become lean strong and physically fit (p25). Impairment and ill-health are no longer seen to arise as a consequence of bad luck or misfortune, but as an individual's failure to live right, eat well, exercise and so on. This individualisation of health can lead to stigmatisation of any who do not conform to the professionally determined 'norms'. Similarly, Crawford argues that health has become '...an important symbolic domain for

creating and recreating the self' (1994; 1356) and that the concept of health is central to modern identity. In a similar vein to that of Shakespeare, he goes on to suggest that 'The 'healthy self' is sustained in part through the creation of 'unhealthy others', who are imagined as embodying all the properties falling outside this health signified self' (p1358). What is lacking in Shakespeare's work, is an analysis of the experiences of impairment, as these themselves are representations of society, as Schepper-Hughes and Locke argue.

Attention has also been drawn to the less than effective manner which the social model reconciles dimensions of gender (Campling, 1981; Morris, 1991; Lonsdale, 1990), 'race' and ethnicity (Hill, 1992; Stuart, 1992, 1993; Vernon 1996), class (Williams, 1983), generation (Shakespeare and Watson, 1997) identity (Shakespeare 1996) and sexuality (Hearn, 1991; Shakespeare *et al.*, 1996) within or alongside disability. It could be argued, following Shakespeare (1994), that the bracketing of impairment, a central tenet of the ideology of the social model, is the cause of the inability of the social model to provide explanations in many of these examples.

Many of these critical voices have encountered strong opposition from within the British disability movement and disability studies. Indeed, leading activists and academics have been remarkably unwilling to adapt or revise the social model itself. In response to calls for the consideration of impairment, Mike Oliver (1996) has responded by suggesting the creation of a separate 'social model of impairment', and in response to those who have criticised the inadequacy of the social model, he has claimed that it was never intended to be an exhaustive social theory.

¹⁰ Needham (1973) points out that the symbolic representation of the left as inferior, dark and dirty and the right as superior, light and dominant, is used to

Social model theory rests on a distinction between impairment, an attribute of the individual body or mind, and disability, a relationship between a person with impairment and society. A binary division is established between the biological and the social (Oliver, 1996, 30). As with second-wave feminism, the move enables disability studies to illustrate that disability can only be understood in specific socio-historical contexts, and that it is a situation which is dynamic, and can be changed.

Yet, within feminism, the sex/gender distinction has largely been abandoned (see for example Butler, 1990). Theorists and activists do not thereby root woman's being in biology, as the patriarchal tradition has done. Instead, it is observed that sex itself is social. Everything is always already social. Hood-Williams concludes his discussion of the problems of dualism by saying:

The sex/gender distinction dramatically advanced understanding in an under-theorised area and, for over twenty years, it has provided a problematic which enabled a rich stream of studies to be undertaken, but it is now time to think beyond its confines. (Hood-Williams, 1996, 14)

The same, surely, applies to impairment. Impairment is not a pre-social or pre-cultural biological substrate¹¹ (Thomas, 1999, 124).

The social model, by its very nature, rests on a fairly unreflexive acceptance of the disabled/non-disabled distinction. There is an essentialist and totalising understanding of

justify particular social values and social arrangements.

¹¹ This is explored more fully in the next chapter

disability as a category. The awareness that the current understanding of disability and disabled people are historically contingent appears to have few implications for the degree to which it is utilised in the social model, or for that matter in the interactionist accounts, as a stable descriptive classification. Disabled people are seen as those who identify as such (Oliver 1996) or who can be identified as such. But Liggett argues:

From an interpretative point of view the minority group approach is double edged because it means enlarging the discursive practices which participate in the constitution of disability. [...] [I]n order to participate in their own management disabled people have had to participate as disabled. Even among the politically active, the price of being heard is understanding that it is the disabled who are speaking." (1988, 271ff)

Liggett is following those post-structuralist authors who point out the costs to identity politics. To be an activist - whether as a gay person, or a woman, or a disabled person - is to make the label into a badge, to make the ghetto into a oppositional culture. Yet what about those who wish to be ordinary, not different? Liggett is, in effect, arguing for a collapse of social classification.

The social model could not be described as ahistorical, but it does presuppose that disability is a bounded category with a singular intrinsic meaning. Whilst the issues surrounding disability might change, the crucial essence stays the same. Disability is allocated the status of a signifier and research aims to address the problem of disability. Disability is taken as a given. Disabled people and disability are positioned as part of well worn dichotomies (such as impaired/nonimpaired, body/society, therapy/emancipation, resistance/conformity, domination/subordination). This is

underpinned by an understanding of power as global, coercively subordinating disabled people. Thus a powerful ruling class, or capitalism as Oliver (1990, 1996) depicts it, is positioned as dominating powerless disabled people. Disabled people are unable to reach their full potential due to the repressive effects of a nondisabled society.

What is needed is an analysis that provides an alternative to these customary views, one that rejects these simplistic dichotomies, rejecting the idea of disability or disabled people as a coherent 'fact in itself'. Mairian Corker (1999) has been a pioneer in applying such ideas to the field of disability. To achieve this shift, it is necessary to employ a more subtle and flexible understanding of power than is found in much of the social model theorising and to extricate disability from the binary oppositions in which it is usually located.

Conclusion

The central aim of this chapter has been to outline the various approaches to sociological writings on disability. It has examined the conceptual framework behind symbolic interactionist approaches, phenomenological accounts, socio-medial models and the social model of disability and it has explored the critiques of each approach.

The chapter began by outlining the central tenets of structural functionalist accounts and argued that such approaches have limited value in writing on chronic illness and impairment. It then moved on to examine symbolic interactionist accounts, which allow an investigation of the lived world of disabled people through which an understanding of disability that is embedded in the everyday experiences of disabled people emerges. However, many such accounts have been judgmental, they have failed to address issues of inequality, powerlessness and violence. The focus is on the individual and the work

can merely serve to reinforce notions of normality and abnormality. Phenomenological accounts are also individualistic and provide little or no analysis of the structures in which disabled people operate. The focus on meaning, whilst useful in that it allows an analysis of how people with impairment can reconstitute their self following the onset of the condition, brackets out existence, the 'real' world from which disabled people are excluded.

The socio-medical model, with its reliance on medical definitions and its linkage between impairment, disability and handicap also down plays the importance of the environment. In addition, it leads to the medicalisation of disabled people and places them in a dependent position.

Finally, the social model of disability was reviewed. This model, has undoubtedly been important in both sociological and political terms. However, its reification of the social and its bracketing of impairment precludes the emergence of a full picture of the experiences of disability or impairment. Disability is more than either social or medical and any analysis must include all the dimensions of disabled people's experience. The social model's rejection of impairment as a significant aspect in disabled people's lives was identified as particularly problematic. It is to this issue of the body and embodied experience that this thesis now turns. The next chapter will outline some of the writings on impairment and the body from various theoretical positions.

Chapter 2

Theorising Impairment

Introduction

The body has become central to the sociological project. We have moved from what Freund described as a 'curiously disembodied view of human beings' (1988:839) to one in which 'bodies are in, in academic as well as in popular culture' (Frank, 1990:131). This, as Frank (1991) suggests, is, in part, be attributed to the influence of Foucault and in part due to recent developments in feminism. In addition, as Falk (1994) argues, there has been a cultural shift which has resulted in the individual being seen as a consumer rather than a producer with the body being seen as the end product of this consumption. This chapter reviews some of the recent debates in the sociology of the body and disability studies and argues the case for inclusion of a notion of embodiment in theorising disability.

The chapter aims to reclaim the impaired body from the mostly naturalistic accounts of impairment found in much of the writings in sociology of the body, thus challenging the imposition of biomedical and biological assumptions. It also aims to argue against the Cartesian dualism upon which the social model is based. In this way the approach is similar to that adopted by Scheper-Hughes and Lock (1987) in their appeal to the body as a 'prolegomenon to future work in medical anthropology'. Consequently, it does not aim to provide a comprehensive review of sociology of the body. Such reviews can be found in the work of Shilling (1993), Falk (1994), Synnott (1993), Turner (1996) and Frank (1995).

This chapter will look at three approaches to the treatment of impairment and the impaired body. First is the disability studies approach. In this approach the body is bracketed and impairment seen as an unnecessary distraction from the political agenda that lies at the heart of disability studies. This is exemplified by the work of Oliver (1990, 1996) and Barnes (1996) and also more recent work by Thomas (1999) which has sought to supplement the social model with a focus on what she terms 'impairment effects'. Second, are the postmodernist or post-structuralist approaches which deconstruct and problematise the notion of impairment, as found in the work of Price and Shildrick (1998) and Corker (1999). Third is the approach of Hughes and Paterson (1999, 1997) which seeks to develop an understanding of impairment through phenomenology. The chapter will then examine the writings of Douglas and Scheper-Hughes and Lock (1987) who have sought to try and examine the body through a variety of means. The concludes with a section on embodiment, drawing particularly on the work of Csordas (1990, 1993, 1994), and seeks to set an agenda for the study of the impaired body.

The body in disability studies

The issue of the body and embodiment is problematic for disabled people themselves and disability theorists. The social model, with its emphasis on environmental and social barriers, brackets the body, arguing that disability has nothing to do with the body (Oliver 1996a). The materialist arguments of Oliver and others have a set up a Cartesian dualism in which disablement (the social) and impairment (the biological) are treated as two independent categories. For Oliver, impairment 'is in fact nothing less than a physical description of the body' (1995;4). The assumption appears to be that you can have a value free biological description of the body¹. Impairment is seen as a diversion from the overtly political approach of disability studies and any attempt to include it in theorising disability merely adds additional and unnecessary levels of complexity. As the Northern Officer Group (1996) put it:

The social model does not deny the existence of impairments and physiological differences...; rather, it addresses them without attaching value judgements such as 'normality' and shifts emphasis towards those aspects of our world that can be changed.

Disability, they argue, should be considered as a social phenomenon and is about discrimination and exclusion. Such social processes operate largely independently of the experience of people with impairments. The fact that two people experience their impairments in different ways and construct differing identities for themselves is important but it does not necessarily mean that one will be discriminated against any more or less than the other. The materialist and modernist approach prevalent within disability studies disembodies the experience of disablement, ignoring bodily experience altogether. The body in general, and impairment in particular become a neutral substratum on which power/discourse debates are acted out. The body is 'black-boxed' in favour of a political analysis with a focus on barriers to participation.

Given that the predominant medical paradigm defines disabled people on the basis of their impairment and that the body, or more particularly the disfunctioning body, is seen as the defining characteristic of disabled people, this rejection is understandable. Any theory of disability that includes a notion of embodiment runs the danger of locating disability within the individual, presenting the problems that disabled people face as a consequence of their functional limitation. Thus for reasons of political expediency and radical rhetoric, disability studies has neglected the body in favour of a structural analysis (Shakespeare & Watson

¹ Oliver (1996) has, however, argued that what is needed is a social model of impairment, which, whilst suggesting that he no longer seems to agree with a impairment as a value free description, does reinforce a notion of Cartesian dualism.

1995a).

However, as many argue, this separation is problematic. Disabled feminists such as Morris (1991, 1996), French (1993), Crow (1996) and Thomas (1999) have expressed disquiet at the omission of impairment and bodily experience. So Morris writes:

We can insist that society disables us by its prejudice and by its failures to meet the needs created by disability, but to deny the personal experience of disability is, in the end, to collude in our oppression. [Morris, 1991,]

and Crow

The experience of impairment is not always irrelevant, neutral or positive. How can it be when it is the very reason used to justify the oppression we are battling against? How can it be when pain, fatigue, depression and chronic illness are a constant fact of life for many of us..... We need to focus on disability and impairment; on the external and internal constituents that bring together our experiences. Impairment is about our bodies ways of working and any implications that holds for our lives. Disability is about the reaction and impact of the outside world on our particular bodies. One cannot be fully understood without attention to the other, because whilst they can exist independently of each other, there are also circumstances where they interact' (Crow, 1996)

Crucially, however, these writers share the social model's focus on barriers, but argue that to ignore the experience of impairment at the expense of disablement fails to explain fully life as a disabled person. There are bodily dimensions to both disablement and impairment; pain, incontinence, sexual function and fatigue. These can become marginalised within the rhetoric associated with the social model.

The suggestion is that by exploring and documenting the role of impairment, by bringing in a 'bit on the body,' the shortcomings of the social model can be overcome. Whilst attractive, such an approach is unsustainable. Impairment, on both an individual and a societal level, is embedded within the social. As Connell argues:

...it is not enough to assert the importance of bodily difference, important as this has been in recent feminist theory. We need to assert the activity, literally the *agency* of bodies in social processes.I want to argue for a stronger theoretical position where

bodies are seen as sharing in social agency, in generating and shaping courses of conduct. (Connell 1995;60)

In his later work on sexuality Connell (1997) argues that strongly social constructionist approaches run the risk of ignoring the bodily experience of sexual practice altogether. In the same way that Connell argues that sexuality is a bodily process which focuses on the embodied experiences of erotic and reproductive potentials, so disablement is an embodied experience.

Hughes and Paterson (1977, 1999) take a similar approach to this with respect to impairment. They write:

In the social model, the body – reduced to impairment – is afforded only instrumental and objective status. It reproduces the empirical body of medical intervention. This highly restricted ontology eliminates the 'lived body' (leib) and as a consequence, has nothing to say about the bodily point of view of disabled people or the embodied experience of prejudice and oppression, disadvantage and discrimination. (1997; 337)

If the body is to be incorporated within disability studies, as it surely must be if it is to overcome its Cartesian failings, then to suggest as Oliver (1996) has done, the development of an unspecified social model of impairment to sit alongside the social model of disability, is inadequate. Such an approach would merely serve to reinforce this dualism. The body is central to social relations and processes, it is both a site of marginalisation and a site of resistance:

The body is not only a symbolic field for the reproduction of dominant values and conceptions; it is also the site for resistance to and transformations of these systems of meaning. Cultural meanings are not only shared or given; they are fragmented and contested (Crawford 1984:95)

What is needed is a collapsing of the boundaries between the biological and the social for, as Freund points out:

Thus to understand the social construction of bodies is to understand how differences that are often taken to be 'natural' are in fact socially constructed in nature. Even if we accept these differences as 'intrinsic' and 'natural', this should not preclude recognising the role that social construction plays in amplifying them' (1988:855)

Having looked at the place of the body in disability studies, this chapter now moves on to examine approaches that seek to incorporate the body into theorising about disability.

Materialist Challenges to the Disability Studies Canon

The recent work of Carol Thomas (1999) has gone some way towards meeting the criticisms outlined above. She writes as both a medical sociologist and a disabled feminist and her work is influenced by writers from disability studies, medical sociology and feminism. In addition to the writings of Oliver and Bury, she has drawn on the work of Morris (1989, 1993, 1996), that of the Canadian philosopher of disability, Wendell (1996) and the feminist scholars Stanley and Wise (1990, 1993) to provide an analytical framework for the study of disability. To this end, she has coined the term 'impairment effects' in her attempt to include the body and impairment in explorations of disability. She argues that the UPIAS definition, and the social model, 'does *not* assert that *all* disadvantages and restrictions of activity experienced by people with impairment constitute disability' (p42 emphasis in original). The social model does not suggest that restrictions caused by physical, sensory or intellectual impairments do not exist, it is just that they are not disabilities. However, when these restrictions are used to discriminate against an individual they become a disability. Impairment effects, she suggests, refer to 'the restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense' (p43). However, as she makes clear, impairment effects are not pre-social, but are 'shaped by the interaction of biological and social factors, and are bound up with processes of socio-cultural naming' (p43). Importantly, her work also includes an exploration of psycho-emotional well being which she links to the impact of both disabling barriers and impairment effects.

Thomas is overtly materialist in her approach and her work does not try to challenge the social model but to modify it. She seeks to develop what she describes as a 'non-reductionist, materialist ontology of the body' (Thomas 1999; 143 and in press). For her, disability should still be seen as a consequence of social relations, but that this understanding needs to be supplemented with an inclusion of impairment effects. As she concludes at the end of her book:

The lived experience of many people with impairment in society is shaped in fundamental ways by the interaction between, and the accumulative impact of, disability (and disablism) and impairment effects. However, a careful analytical distinction needs to be made between the consequences of disability and impairment effects. The most fruitful way forward is to develop an approach which understands disability as a form of social oppression, but which finds room for the examination of impairment effects. (*op cit* 1999; 156)

Disablement and impairment effects, according to her analysis, interact, impacting on an individual's emotional and psychological well-being, causing restrictions in activity. However, the same criticism that was applied to the social model in the last chapter can also be applied to this work; that is that it rests on an unreflexive acceptance of categories, be they either impaired/non-impaired or disabled/non-disabled. Whilst she examines the work of feminists who challenge the creation of these categories (for example the work of Fuss 1989 and that of Price and Shildrick, discussed below), their analysis is rejected in favour of an approach in which difference, in the form of impairment effects, is accepted. So she writes:

I do not accept the postmodernist view that any ideas about the 'human body' being a real material entity, with morphological, anatomical and genetic characteristics which exist independently of 'scientific' and other discourses about the body, automatically signals a descent into a modernist ontology of the 'fixed', 'unchanging', and 'transhistorical' human body with an accompanying categorisation of bodies into 'normal' and impaired types, and a belief that the biological will determine the social. (*op cit* 1999; 143)

At the end of the day, what she is arguing for is a social model that includes a bit on impairment, but that such an analysis of impairment can be seen as separate from disablement, hence the use of the term 'impairment effect'. Whilst her approach is more sophisticated than Oliver's (1996) it is, in essence the same. Disablement and impairment can be separated and should be treated as such. Where she differs from Oliver is in her overt acknowledgement of impairment and the impact that having an impairment can inflict on an individual's psycho-social wellbeing, an area completely bracketed by social model theorists. However, as indicated earlier, some, such as the Northern Officers Group (1996), would suggest that the social model does not preclude impairment, it is just that impairment is not seen as changeable so is of little interest to the disabled people's movement. Her approach is, in effect a compromise, in that she rejects crude biological determinism and strong social constructionism, but she fails to present an analysis that embodies the experience of disability/impairment. The social is still presented as separate from the body. However, her work is important in that she produces a materialist understanding of impairment, something which is lacking in the writings of postmodern theorists discussed below.

Challenging the Categories: Poststructuralism² and the social model

The post-structural theorists Margaret Shildrick and Janet Price have attempted to deconstruct and problematise the notion of disablement/non-disablement, impairment/non-impairment and

² I do not intend here to enter into a debate about the meaning of poststructuralism or postmodernism, but instead use them as convenient descriptors of a trope.

the body (Price and Shildrick 1998, Shildrick and Price 1996, Shildrick 1997). They challenge constructions of impaired/non-impaired, disabled/non-disabled as they apply poststructuralist perspectives to the body. Using the work of Butler (1990, 1993) who argues that feminism, inadvertently, reinforces the gender order, they suggest that disability studies and the disabled people's movement also reinforces the normative order (Price and Shildrick 1998; 234). Butler contends that feminism, through using the category of women as a foundation for feminism, creates the idea of an homogeneous category of 'women'. She suggests that calling for the emancipation of women and their inclusion in the social order further specifies the category of women, leading to greater exclusion and dis-empowerment for some women. So Butler writes:

..theories of feminist identity that elaborate predicates of color (sic), sexuality, ethnicity, class and able-bodiedness invariably close with an embarrassed 'etc' at the end of the list. (1990;143)

What Butler and others urge is a challenge to the binary gender order, the fixed dichotomy of male/female. She challenges the very idea of gender identity, displacing the notion of women as the foundation of feminist politics, making the category 'women' open, allowing for alliances between other oppressed groups to meld with women.

Shildrick and Price (1996), from the standpoint of Butler's performative theory, seek to challenge the dichotomy disabled/nondisabled, collapsing the notion of a 'them' and 'us', challenging the very idea of the concept of an impaired body. The body, they argue, should be seen as a discursive construct and that 'the physical impairments underlying disability can no longer be seen as essential biological characteristics of a 'real' body, upon which a disability is imposed. Rather they are themselves constructs held in place by the regulatory practices that produce and govern bodies' (Shildrick and Price, 1996;98). Their work is heavily influenced by the writings of Foucault, especially his later writings on technologies of the self (Foucault 1988). They use the work of Fuss to suggest that by deconstructing the very notion of identity based on any embodied characteristics they can challenge the binary order impaired/non-impaired. Deconstruction, as Fuss argues:

...dislocates the understanding of identity as self-presence and offers, instead, a view of identity as difference. To the extent that identity always contains the spectre of non-identity within it, the subject is always divided and identity is always purchased at the price of exclusion of the other, the repression or repudiation of non-identity (Fuss 1989; 102-103).

For Fuss, the identity of a person is implicated in its opposite; from this perspective, impairment only exists in relation to its opposite, non-impairment. People who are impaired, and identify as such, place themselves within a social hierarchy in which they are situated as deviant. The challenge for disabled people becomes one of contesting the very category that is used to define them, the dichotomy impaired/non-impaired or to challenge its deviance and celebrate rather than negate difference. The boundaries between impairment and non-impairment are fluid, constantly open to challenge and change, and are the product of discursive practices. But these discursive practices are not the sole property of other powerful groups such as the medical profession, but are also constituted through the writings of those who purport to argue for the inclusion of disabled people (Price and Shildrick 1988). The body is not, they suggest, a category or a signifier, there are no binary divides, there is no notion of impaired/non-impaired or disabled/non-disabled.

Mairian Corker (1999, 1998) takes a similar stand. By drawing on Butler, who writes:

The methodological domain of women's studies is that which includes any research that treats gender (whether female or male) as a central category of analysis. The parenthetical reference to female or male suggests that these terms are interchangeable with the notion of gender, although conventional formulations of sex/gender distinction associated 'sex' with male and female – or with the problematic of a continuum between them – and gender with the social categories of men and women. This suggestion...that gender might be understood as equivalent to 'female or male' thus appears to rest on a conflation of sex with gender. (Butler 1997; 4 in Corker 1999;636)

Corker argues that such a danger exists for disability studies; that is, that impairment and disablement might themselves become conflated and that any separate sociology of impairment might end up working against the social model of disability. Coming as she does from a sociolinguistic background, she uses the work of Derrida to argue that the project for disability theory should be to contest meanings. She contends that Derrida argues that binary opposites, in which one term is given precedence over the other, exist so as to 'deceive us into valuing one side of the dichotomy more than the other' (1999; 638). Through challenging such meanings and seeking to break down binary opposites the concept of disability and impairment can be conceptualised so as to present the problems faced by disabled people as being produced in the relationship between impairment and oppression. This contrasts with a social model analysis which presents disability as the collective experience of oppression.

This work is interesting and challenging. However, no advice is given as to how the challenge to existing categories could be made and their ultimate goal is unclear. If, as Shildrick and Price (1996) and Liggett (1989) suggest, the category disability is abandoned as a foundation

and all identities and stable categories are contested, what replaces it? To paraphrase Seidman (1994;254), disabled people need a positive, unitary image to create solidarity and to challenge disablist stereotypes. Their approach is vague and abstract, lacking in any materialist understanding of what it is to be human. Representations of experience are, to a large extent, absent. Indeed, it could be argued that postmodernist approaches are as disembodied as social model theorists in that the body and or impairment merely becomes a text, a problem of language, a surface on which social meanings are ascribed and on which the interplay between power/knowledge is acted out (Connell 1995, Cunningham-Burley et al 1995). Issues of identity, otherness and difference cannot be discussed without reference to political or material circumstances (Harvey 1993). Bigwood puts this eloquently:

If we reduce the body as a whole to a purely cultural phenomenon and gender to a free-floating artifice, then we are unwittingly perpetuating the deep modern alienation of our human being from nature (Bigwood, 1991, 59).

There is little or no emphasis on the body as lived, as active. The body is a corporeal entity, it is a 'lived body', it exists outside of power/discourse (Frank 1996). In an attempt to meet these criticisms, it is to phenomenological approaches to the body that this chapter now turns,.

Experiencing Impairment: Phenomenological Approaches

This section explores some of the major writings on phenomenology and the body which can be applied to impairment. It starts by exploring the work of writers who have written about the experience of impairment, it moves on to look at idea of the body as a 'taken for granted' and finally explores the issue of embodiment.

Experiencing Impairment

Hughes and Paterson (1997, 1999) have made similar critiques of much of the postmodernist writings on the body to that outlined above. They argue that it:

replaces biological essentialism with discursive essentialism. The body becomes nothing more than multiple significations that give it meaning. Post-modern consciousness actually annihilates the body as a palpable, natural material object. The body and the sensate – in effect – disappear into language and discourse, and lose their organic constitution in the pervasive sovereignty of the symbol. (1997; 333)

For Hughes and Paterson phenomenology, with its emphasis on lived experience, meaning and the carnal body provides a way through the dualism of disablement/impairment set up by Oliver and other disability studies writers. They use the work of a variety of phenomenologists in their attempt to theorise embodiment and to develop what they term a social model of impairment.

Phenomenological literature varies greatly in what role it assigns to the body, but in the writings of Merleau-Ponty it is perhaps the most explicit (Lyon and Barbalet 1994). In this work the body is not a product of discourse, but is a function of being in the world. Perception, for Merleau-Ponty (1962), is grounded in the experienced and experiencing body. It is through the body that all information and knowledge are received and meanings are produced (Grosz 1994; 87). By using a phenomenological approach to the body Crossley has developed what he calls a *carnal sociology* in that it:

..addresses the active role of the body in everyday social life. It is concerned with *what the body does* and it stresses and examines the necessarily embodied bases of the praxical-symbolic constituents of social formation. (1995; 43, emphasis in original)

Merleau-Ponty, Crossley argues, moves beyond an understanding based on the notion of the body as object towards a position that recognises that agents are embodied, and that the body is an articulative, communicative being. Cartesian dualism is thus collapsed, the body becoming both subject and object. Grosz (1994; 94-95) argues that the work of Merleau-Ponty offers three crucial insights. First, by privileging experience, whilst at the same time acknowledging how social, cultural and historical forces can shape it, its role in both the inscription and subversion of values can be examined. Second, by taking experience seriously and according it a direct relevance, it can act not only as a starting point for analysis but also as a measure against which theory can be tested. Third, by locating experience midway between the body and consciousness, actions and thoughts become embodied 'located in and as the subjects incarnation' (p95).

For Hughes and Paterson phenomenology allows the development of a sociology of impairment that 'embodies the addition of sentience and sensibility to notions of oppression and exclusion' (1997; 335). They contend that if, as Crossley (1995) suggests, the social is embodied and the body is social, then it follows that 'disablement is embodied and impairment is social' (p336). The illness, that is the social experience of the condition, rather than the pathological details of the disease becomes the focus of attention (Williams 1995). This has formed the approach of many of the first hand accounts of the experience of chronic illness and those based on what may be loosely termed narrative, for example Frank (1991, 1995), Kleinman (1988), Murphy (1987), Toombs (1992). It is in these narratives that the body, the personal experience of impairment and the cultural representation of the body collapse. Kleinman (1988) describes these as illness narratives, through which 'patients order their experience of illness' (p49), he continues:

The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long term course of suffering. The plot lines, core metaphors, and rhetorical devices that structure the illness narratives are drawn from cultural and personal models for arranging experience in meaningful ways and for effectively communicating those meanings. Over the long course of chronic disorder these model texts shape and even create experience. The personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering.

These narratives are themselves embodied. The illness narrative is a narrative based on the experience of living with a diseased body (Frank 1995). It is this experience that phenomenology seeks to uncover, concerned as it is with the 'lived body'. As Leder argues '...the body is not simply a thing in the world, but an intentional entity that gives rise to the world' (1992;27). Physicality, that is biology and biomedical descriptions of the body, become bracketed in favour of an analysis based on experience, one that allows choice, and responsibilities (Frank 1995).

Hughes and Paterson (1997, 1999), from a disability studies perspective, illustrate how a phenomenological approach to the body and impairment can challenge the stereotype of a disabled person as a victim. The concept of 'suffering' they argue, has reactionary and tragic overtones. However, by reversing impairment and disability the concept of suffering can be redrawn as one that reflects both oppression and pain, thus politicising the medical and exposing the disablist society in which we live.

A phenomenological approach to suffering in which the reversibility of impairment and disability made it possible to think of suffering as a concept which reflected the mutual engagement of pain and oppression may be a way of reflecting the fact that disabled people do suffer. However, at the same time, by foregrounding of the concept oppression, suffering is removed from its connective association with a charitable response to tragedy. To recast suffering as a dialectical concept on the threshold between pain and oppression not only politicises the medical, but exposes the disablist basis of the charitable disposition. (1997; 336)

Disablement thus becomes embodied as suffering. Impairment becomes social through the narrative, and whilst this removes it from the 'intercorporeal' it is impairment that structures this 'felt world'.

In their later work (1999), they describe the experiences of Paterson in his everyday life, how his social environment reminds him of his body. The disablist attitude of others, they argue,

adds a temporal as well as a spatial element to the experiences of impairment. The body *dys-*appears in encounters with others, yet can disappear at other times. Oppression, they argue 'is not simply an abstract structure manifest, for example, in exclusion from the labour market – it is felt in the flesh and bones. It erupts in the body as the body *dys-appears*' (p 606). Interactions with non-disabled people demand an adoption of bodily conformity, one that most closely parallels non-impaired norms, which in turn demands a rejection of disabled people's own carnal embodiment. Disablist practices thus alienate impaired people from their own body. Action, they suggest should be targeted at the way that non-disabled people read the impaired body, for, as they argue:

It is not my performance, or my reaction to my performance, which needs to be modified to prevent my exclusion, but the scripts from which non-disabled people judge and bestow 'social competence'. Such an approach suggests a radical praxis of inclusion, a struggle to carnally re-inform the codes of timing and proprioception which structure participation in the lifeworld. (1999; 607)

Thus, for them, a social model of impairment and through this a challenge to the materialist bias inherent in much social model theorising, is one that not only confronts the social exclusion of disabled people, but also one that examines the production of impairment and the embodiment of oppression and discrimination.

Phenomenology, however, is more a philosophy than a sociology (Turner 1996). By taking its account of embodiment from the perspective of the subject it can become ahistorical, ungrounded in the social and the material. It is what Bourdieu terms unreflexive, in that:

..[it] sets out to reflect an experience which by definition does not reflect itself, the primary relationship of familiarity with the familiar environment....But it cannot go beyond a description of what specifically characterises 'lived experience' of the social world.....this is because it excludes the question of the conditions of possibility of this experience...it is also because... it excludes any inquiry as to its own social conditions of possibility and more precisely as to the social meaning of the practical *epoche* that is necessary in order to conceive the intention as to primary understanding .. (1990; 25-26).

The structural issues that impinge on our relationships with our bodies, be they governmental, cultural or economic are bracketed out in favour of an analysis based on meaning. It is an individualistic philosophy and as such it is unable to tackle issues of inequality, racism, sexism and disablism (Turner 1996). Disabled people, under the medical gaze, often lose control of

their bodies, indeed some are seen as having no control of their bodies, and it is this governmentality of their bodies that phenomenology is unable to grasp.

Shakespeare and Watson (1995a) have sought to overcome this shortfall by arguing for what they term an 'ethnography of physicality'. Attention, they argue, should be focussed on the denial of physicality in general, and impairment in particular, by the non-disabled population. That is, rather than impairment being the defining characteristic of disabled people, it could be seen as the central element in embodiment. That is to say, human embodiment is characterised by frailty, limitation, and ultimately by death. Zola (1983,1989), drawing on the work of Foucault (1965, 1973), Dubos (1959, 1965) and Stone (1984), argues that such an approach would prevent many of the problems that are inherent in current literature on disability in that it removes the emphasis from what distinguishes disabled people from non-disabled people, to what links them. Phenomenological and constructionist approaches serve to reinforce distinctions between non-disabled and disabled people. If impairment is viewed as a normal and accepted part of our existence, then theorists will cease to write about disabled people as 'them' which contributes to their distancing and isolation.

The ever-present reality of morbidity and mortality in human populations means that a Cartesian dualism which focuses on mind and reason as constitutive of humanity, and neglects body and its impairments, is prone to idealism. Disabled people cannot be distinguished from non-disabled people on the basis of the fact of impairment, because both groups experience impairment and limitation. There may be a quantitative difference in impairment, but qualitatively, there is no separate status of people with impairment. Or as Zola (1993) puts it, 'Everyone has got one or will, and they will likely have them a lot longer than anyone realises'.

Shakespeare and Watson argue for a need to problematise the lived body. Given the ubiquity of impairment what is needed is an understanding of how people maintain their body as unproblematic. In the same way that Antonovsky (1979) argues for a salutogenic approach to health, where the normal state of affairs is one of entropy, of disorder and of disruption of homeostasis, they argue for a continuum conceptionalisation in which the body is placed somewhere between the imaginary poles of total impairment and the complete absence of impairment.

The body as taken-for-granted

If these points are accepted, it follows that if the embodied experiences of disabled people are to be theorised what is needed is an approach that explores the body as taken-for-granted, That is, rather than exposing the impaired body, it should be seen merely as a body that people

live with. Generally, the disabled body is naturalised within much medical sociology and sociology of the body. Physical inadequacy is taken as the defining element of disabled people's experiences. For example, Shilling writes:

We all have bodies, but we are not all able to see, hear, feel, speak and move about independently. Having a body is constraining as well as enabling, and people who are old or disabled often feel more constrained by their bodies than do those who are young and able-bodied. (1993;23)

However, despite the embodied nature of impairment, it is rarely mentioned. For example, when Turner does talk about disability, it is to break his usual practice of regarding the body as entirely socially constructed. Disabled people, it seems, exist for Turner only to show that the body can occasionally, really, be limiting (Turner, 1992; 41). Frank (1991) himself makes clear that his schematic does not apply to disabled people. Disabled people, as far as Frank is concerned, are a residual category. As he puts it:

It is not a condition which fits my diagram thus demonstrating that any theory must have its residual categories. (1991; 87)

Not only are disabled people to be denied access to full membership of society, they are also to be excluded from social theory (Oliver 1996b; 19). Sociologists of the body are guilty not only of taking a normative stance and neglecting disabled people's experience, but also of ignoring the conceptual developments arising out of the disability movement, and Disability Studies, for example notions of the disabling environment, and the social model. It is these normative assumptions that surround much of the literature on the body that could be seen as a reason why disabled theorists have resisted the recent trend towards the study of embodiment. As Davis writes:

The disabled body is a nightmare for the fashionable discourse of theory because that discourse has been limited by the very predilection of the dominant, ablist culture. The body is seen as a site of *jouissance*, a native ground of pleasure, the scene of an excess that defies region, that takes dominant culture and its rigid power laden vision of the body to task. The body of the left is an unruly body: a bad child thumbing it's nose at the parent's bourgeois decorum; a rebellious daughter transgressing against the phalocentric. The nightmare of that body is one that is deformed, maimed, mutilated, broken, diseased.....the critic turns to the fluids of sexuality, the gloss of lubrication, the glossary of the body as text.....But almost never the body of the differently abled (Davis 1995;5)

This approach has not been confined to those whose approach to the body tends to be theoretical. For example, Jonathan Watson (1998) has recently argued that there are certain circumstances in which the researcher can approach the body directly, one such being people with a chronic illness. He cites for example, the work of Kleinman (1988) and Murphy (1987). This seems to suggest from the outset that the presence of an impairment alters the relationship to the body. From what he implies it seems as if disabled people cannot and/or do not take their body for granted and that there is little or no need to develop conceptual tools or methodologies to facilitate access to such taken-for-grantedness. If such a thesis is taken as the starting point for research into the body and disability, it is no wonder that much research reinforces the idea that disabled people's sense of embodiment is different to non-disabled people, as found, for example, in the work of Williams and Barlow (1998). In the work of Watson et al (1996) and Cunningham-Burley et al (1995) similarities between the embodied experiences of disabled people, young men and people of middle years were clearly identified. What is needed is to approach the body and issues of embodiment so as to ascertain the experience of having an impairment both as sensation (experienced in the mind and body), and as experienced in the social. The work of Bob Connell in his analysis of gender relations (1987) and masculinities (1995) is an exemplar of this type of work. He shows how social processes define the gendered body, but goes further than most feminist theorists when he suggests that it is the activity or agency of bodies, what Bourdieu (1977) would term bodily practice, that needs to be prioritised. Connell argues for a position 'where bodies are seen as sharing in social agency, in generating and shaping the course of social contact' (1995;60). It is the embodied experience of disabled people that should be explored, taking as its starting point the understanding that such an approach, as Csordas writes, 'requires that the body as a methodological figure must itself be nondualistic, that is, not distinct from or in interaction with an opposed principle of mind' (1990; 8). Through such an approach disabled people's own ideas about their bodies, their sense of embodiment, their lived experience can emerge. Sociological analysis of the impaired body needs to move away from discussing how disabled people make sense of their impairment, rejecting the idea that impairment signified 'trouble', as found in much of the previous research on disability and the body, embracing an analysis of the taken-for-granted, everyday nature of living with impairment. This entails an approach that has at its centre an exploration of embodiment.

Embodiment

Two of the most influential writers on embodiment have been the British anthropologist Mary Douglas (1966, 1970) and American anthropologists Nancy Scheper Hughes and Margaret Lock (1987). Both of these writers have suggested sociological and anthropological schemas through which the body can be conceptualised.

Douglas distinguishes between two bodies: the symbolic social body and the physical body. In *Natural Symbols* Douglas argues that 'the two bodies are the self and society: sometimes they are so near as to be almost merged; sometimes they are far apart. The tension between them allows the elaboration of meaning' (1970;112). For Douglas, 'the social body constrains the way the physical body is perceived'. She goes on to argue;

The physical experience of the body, always modified by the social categories through which it is known, sustains a particular view of society. There is a continual exchange of meanings between the two kinds of bodily experience so that each reinforces the categories of the other. As a result of this interaction the body itself is a highly restricted medium of expression (1970;xiii).

However, her approach to the body produces more of an anthropology of stratification and social location rather than an anthropology of the body (Shilling 1993). Whilst many within sociology of the body might see this as a weakness, it is this aspect of her work that has proved most useful in relation to disability. Shakespeare (1994) shows how, by applying Douglas's concepts, an analysis of the way that normative, dominant views are disturbed or conflicted by anomaly can be produced. Impairment is one such anomaly, but it becomes an anomaly through the social. However, whilst Douglas's schematic is related to stratification, it is not grounded in socio-economic context and, as Shakespeare (1994) points out, she fails to develop a link between culture and material relations. Her distinction between the social and the physical body ultimately fails to incorporate the body, or embodiment, into social theory as it can be read as a replication of the mind/body duality.

The work of Douglas has been integrated with the theorising of both Foucault and Mauss by the medical anthropologists Scheper-Hughes and Lock (1987). Mauss, in his influential essay *Techniques of the Body* (1973 [1934]), described how the body was not only employed as a tool to shape the world, but also as a way of identifying people. The way we walk, dig, swim, rest, sit and so on all in some way say something about us. The cocky strut of the adolescent in compared to the timid walk of an older person down a darkened street, although both have the same objective, send out different messages. Walking, as Oliver (1996) makes clear in his essay on walkers and nearly walkers and the cultural implications of walking, is more than a means of getting from A to B.

Scheper Hughes and Lock's point of departure on the body is similar to that of Douglas, as they state:

We will begin from an assumption of the body as simultaneously a physical and symbolic artefact, as both naturally and culturally produced and as securely anchored in a particular historical moment (1987; 7)

They propose a three body schematic:

1. As a phenomenally experienced *individual body self*; 2. as a *social body*, a natural symbol for thinking about relationships among nature, society and culture; and 3) as a *body politic*, an artefact of social and political control (1987;6 emphasis in original).

The body is thus represented through phenomenology, structuralism and symbolism and post-structuralism. It is the third body, the body politic, that for them is the most dynamic, providing an insight into how and why certain bodies at certain times in history are vilified whilst others are desired. In sickness, suffering and healing, the body and mind are inseparable (hence the title of their paper, *The mindful body*). This mindful body is also inseparable from society.

Sickness is not just an isolated event, nor an unfortunate brush with nature. It is a form of communication - the language of the organs - through which nature, society and culture speak simultaneously. The individual body should be seen as the most immediate, the proximate terrain where social truths and social contradictions are played out, as well as a locus of personal and social resistance, creativity and struggle. (1987;31).

Emotions, in this schema, affect the way that the body, illness and pain are experienced. The authors argue further that it is emotions that provide the 'missing link' between mind and body, individual, society and body politic (1987;28-9). Freund (1992) employs a similar concept, that of 'emotional modes of being', as do Williams and Bendelow (1995). Impairment and disablement, in this schematic, thus become linked through emotions as 'emotions entail both feelings and cognitive orientations, public morality, and cultural ideology' (Scheper Hughes and Lock 1987:28). What is particularly useful about this work is the potential it provides for resistance to dominant views, which individuals can achieve by incorporating their own phenomenological experience of embodiment, challenging the views of others. However, like most of the attempts to incorporate the body into social theory and collapse Cartesian dualities, it could be argued that it merely replaces the mind/body dualism with a mind/body/political schematic.

The anthropologist Thomas Csordas (1990, 1991, 1994) argues that any examination of the body must take as its starting point an exploration of lived experience. Taking what he claims is a more radical approach to the body than that of the more 'traditional' approaches to the body, he argues for an anthropology of embodiment (1994;6). His contention is that most studies on the body take embodiment for granted without problematising it, focusing on the body and its representations, as exemplified in the work of Douglas (1970) and Scheper Hughes and Lock (1987). Embodiment as a standpoint, allows for a rethinking on culture inasmuch as culture is grounded in the human body. His work draws on the phenomenology of Merleau-Ponty and the structuralism of Bourdieu. Drawing on Merleau-Ponty, Csordas argues that bodies are not originally objects to us, but are 'the ground of perceptual processes that *end* in objectification' (1994;7). Objects do not exist outside of perception, and this perception of objects is itself embodied. An object is constituted through intentionality, what it is that we wish to do with it. This is exemplified in the work of Leder (1990) as discussed in the last chapter, who argues that we only make an object of our body when it is brought to our attention, that is it *dys*-appears. Where Leder talks about the *dys*-appearance of the body, Csordas employs the concept of 'somatic modes of attention', that is the moments when the body is objectified. He argues that our understanding of the world is embodied, and the way that we act and move is premised on our own bodily-know-how.

By employing Bourdieu's concept of embodiment, Csordas is able to create a more structuralist analysis than one which merely employs the phenomenological work of Merleau-Ponty. Bourdieu's main focus is on bodily practice, the way that the body has become commodified in modern society (Schilling 1993). At the heart of Bourdieu's writings on the body lies his concept of *habitus*, a system of dispositions which, unconsciously and collectively act as a principle for the generation and structuring of practices and representations. It is an 'acquired system of generative schemes objectively adjusted to the particular conditions in which it is constituted' (1977; 95). His work explores how class determines cultural practices and how culture and aesthetic and social values are propagated. So Bourdieu writes:

The structures constitutive of a particular type of environment (eg the material conditions of existence characteristic of a class condition) produce *habitus*, transposable *dispositions*, structured structures predisposed to function as structuring structures, that is as principles of the generation and structuring of practices and representations which can be objectively 'regulated' and 'regular' without in anyway being the product of obedience to rules, objectively adapted to their goals without presupposing a conscious aiming at ends or an express master of operations necessary to attain them and, being all this, collectively orchestrated without being the product of the orchestrating action of a conductor (1977;72)

Bourdieu maintains that there is little to distinguish between social structures and cultural structures (LiPuma 1993), and that it is through what he calls *economic, social and cultural capital* that an agent can exercise control over both themselves and others. Habitus and capital operate within *fields*, the position of an agent within a given field being the result of the interplay between that agents' capital and their habitus. These three concepts are interrelated, habitus and capital being realised within a given field, capital being a product of habitus and the specificity of a field the product of the habitus of the agents who operate in that field. For example he writes:

Just as economic wealth cannot function as capital except in relation to an economic field, so cultural competence in all its forms is not constituted as cultural capital until it is inserted into the objective relations set up between the system of economic production and the system producing the producers (1990;124).

Habitus is a system, a means by which individual and collective practices are generated (1990;54). It is a process of both socialisation and cultural reproduction (Taylor 1993, Jenks et al 1998).

Habitus is embodied within human beings and exists only because it is inside the head of the actors, through and because of the practices of the actors and is rooted in what Bourdieu terms 'practical taxonomies'³. These taxonomies are at the heart of the generative schemes and are rooted in the body (Jenkins 1992; 75). The embodiment of the habitus is expressed through what Bourdieu terms 'bodily hexis'. It is at this level that the personal interacts with the social.

Bourdieu suggests that social practice is defined and asserted through difference and that individuals and groups recognise how they are different from other individuals and groups. He indicates that the perception of difference involves a dialectic between conditions of existence (based on the distribution of capital) and habitus (the capacity to produce and appreciate practices). He argues that not only is it possible to differentiate people on a structural level in terms of economic capital but that different groups attribute cultural capital to certain behaviour

³ Bourdieu is deliberately vague in his separation of nature and culture. He is, as Jenkins (1992) argues, attempting to show the complexity of a natural world with cultural people living in it. As Bourdieu writes; 'Our and our practice, especially our perception of the social world are guided by practical taxonomies, oppositions between up and down, masculine (or virile) and feminine etc., and the classifications produced by the taxonomies owe their effectiveness to the fact that they are practical, that they allow one to introduce just enough logic for the needs of practical behaviour, neither too much – since a certain vagueness is often

and that they vie to impose their definition of which social phenomena constitute legitimate behaviour. Emphasis is placed on what he terms *physical capital*, the fact that by possessing a body not only can one enter the labour market, but that embodiment itself symbolises power, status, an ability to accumulate and use resources.

By utilising these two theorists, Csordas is able to claim that it is not only our understanding of surrounding objects and environment that is embodied, but also our sense of self and social position. Whilst he recognises that these two approaches are, at times, incompatible, he argues that by using these two approaches he can capture both the process of objectification and the logic of the production of practices (1990; 35). In contrast to the work of Douglas (1970), Csordas is able to claim:

Within the paradigm of embodiment, analysis would shift from perceptual categories and questions of classification and differentiation, to perceptual processes and questions of objectification and attention/apperception (1990;35)

Through an analysis of perception and practice, which are embedded within the body, the manner in which cultural objects (including the self) are constituted and objectified can be investigated (1990; 40).

This approach will not only allow for an exploration of the embodied, lived experience of disabled people and but also enable, provided Bourdieu's idea of habitus is not interpreted just as a process of cultural reproduction but as something less rigid, something that can be challenged experientially, the recognition that people are themselves able to transform cultural and social relations (Davis et al 2000) allowing for the possibility that people's social worlds are characterised by negotiation.

Conclusion

This chapter has presented the case for a need for an understanding of impairment within writings on disability. Whilst it is accepted that the social model, by stressing disablement as a primary axis of social exclusion and rejecting any link between impairment and disablement has been a powerful political tool, its approach presents disablement as a disembodied experience. Disablement becomes a creation that is not embedded in the lives of disabled people but arises as a result of structures. However, as Hughes and Paterson (1997, 1999) comment, disablement is itself an embodied experience. Thomas' work, from within the materialist paradigm of the social model, which attempts to include what she terms impairment effects within an exploration of disability was examined but rejected. Ultimately she fails to

indispensable, especially in negotiations – nor too little since then life would be

incorporate the experience of impairment within her analysis. Her work can still be read as reinforcing a mind/body dualism.

Postmodern and poststructural approaches to impairment were also explored and whilst these were seen as useful in that they challenged the biological essentialism inherent in social model approaches to the body, it was argued that their approach is too abstract and vague to provide a basis for theorising disablement and impairment.

The work of Hughes and Paterson (1997, 1999) was also examined and seen as providing a useful way forward in any attempt to research the experiences of disabled people in that they rejected both the biological essentialism of the social model and the discursive tendencies of poststructuralism. By examining this work with that of Shakespeare and Watson (1995a & b) it was argued that what was needed was an approach that examined the embodied experience of living with an impairment. To this end the schemas proposed by Mary Douglas (1970) and Scheper Hughes and Lock (1987) were examined. Whilst these were found useful, it was argued that they do not really provide an embodied approach to the body, but merely replace Cartesian dualism with a different schematic that was itself built on a split between the body and mind.

Csordas (1990, 1991, 1994) work on embodiment was also explored. This approach provides a particularly useful way into exploring the reality of living with an impairment and disablement. The approach of Csordas would, by emphasising an approach that includes both perception and practice, allow for a reconceptualisation of the experiences of having an impairment, focusing more on the lived experience than that found in the social model, but at the same time, through the notion of habitus and bodily capital, be grounded within the socioeconomic context.

This focus on lived experience suggests an approach that listens to people themselves and problematises their embodiment in an attempt to explore the taken-for-granted, what Connell calls 'the body as is, the body I am' (1987:83). This thesis now moves on to examine ways of exploring the lived experiences of disabled people, whether we can access such experiences and if this provides a useful basis for research and the method adopted in this thesis.

Chapter 3

Researching Disability

Introduction

If sociology, as Seidman (1994) describes it, is to be seen as a public educator, then the role of a sociology of disability must also be to educate on issues of disability. This, however, raises a number of ontological and epistemological issues. Not only are there issues around the definition of disability, as discussed in chapter one, but also issues to do with, for example, the place of experience in research. How best can experience to be explored? How can disability be explored? Whose views are to be given preference? And how are the collected data to be analysed.

One of the effects of research on disability is the production of value systems about disabled people. For example, in the past, the application of the category disability tended to be synonymous with the medical or the therapeutic. Being disabled, or having an impairment, implied pathology, having a deficiency that needed to be treated or adjusted to allow 'normal' capacity to be restored. Disability was thus assigned to medicine and the rehabilitative professions and much research on disability came from within that paradigm. It could also be argued that much sociological research on disability reflects this. Chapter one suggested that disabled people were represented as deviant, as 'not normal', and the focus of research was on the perceived cause of that abnormality, the impairment itself, or on the impacts of labelling or the lived experience of having an impairment.

These beliefs are legitimised through recourse to certain artefacts, that is, data drawn from research in which academics have interviewed disabled people, made notes and examined documents. These data are then organised, summarised, transcribed and presented in a format that others can understand. Through this method sociologists have presented evidence for hypotheses on the nature of impairment and disablement, on the experiences of living with an impairment, and about the nature of social life for disabled people. They argue that through interpretation of data, the immediate world of the experience of being a disabled person can be connected to public issues and to public responses to these issues.

There are a great variety of interpretive approaches to research and almost all have been applied to the study of disability or disabled people at some time or other. For example some have employed the grounded theory approach of Glaser and Strauss (Charmez 1980), some have

applied labelling theory (Scott 1969), and others phenomenology (Goode 1994)¹. Social model theorists have, however, challenged these interpretive approaches. They argue that by focussing 'on individual coping mechanisms, including the management of 'stigma' and other perceived threats to self and identity' (Barnes and Mercer 1997; 4) social disadvantage and oppression is ignored. Consequently, they contend, interpretivism reinforces disability as a 'personal tragedy'. Research on disability they argue must lead to 'the systematic demystification of structures and processes which create disability' (Barnes; 1992; 122). It is this tension in disability research that forms the first part of this chapter. The chapter then moves on to outline and justify the research method adopted in this thesis.

The Disability Studies' Research Agenda

The advent of the social model of disability accompanied by the rise of the disabled people's movement has challenged not only the way that disability itself is theorised, as discussed in chapter one and two, but also the methods employed in academic research on disability (Abberley 1987, 1992). Disability theorists have pointed out the divide that exists between those who are researched, 'the subjects', and those who research, the researchers, and the power imbalance that this creates. Researchers are able to control the design, the implementation, the analysis and the dissemination of their work. Consequently disabled people have little control in the overall research process (Barnes and Mercer 1997). This serves to promote an epistemology that reasserts an essentialist divide between disabled and non-disabled people, between the researched and the researcher. Disability studies claims echo those in feminist theory by, for example Harraway (1988), which argue that the researched are othered, are forced into a position of difference, '...are not allowed *not* to have a body' (p575). Abberley (1987) shows how, throughout much of the research, disabled people are presented as 'passive research subjects' (p141). In addition, the usefulness of research and the motives of academics have been questioned (Oliver 1992, Barnes and Mercer 1997). In a controversial and acerbic attack on research into disability, Oliver (1992) condemns much previous mainstream research in the area as a 'rip off'. He argues that this research has failed to address the social oppression faced by disabled people or to establish an alternative social policy that may bring about an improvement in the lives of disabled people. For Oliver:

Disability research should not be seen as a set of technical objective procedures carried out by 'experts' but part of the struggle by disabled people to challenge the oppression they currently experience in their lives (Oliver 1992:102).

¹ For a comprehensive review of interpretive research approaches see Denzin and Lincoln (1994)

Drawing from the evolving 'critical social research' paradigm of feminist writers such as Lather (1987) and Ribbons (1990) he argues that disability research should become emancipatory. So he writes²:

The development of such a paradigm stems from the gradual rejection of the positivist view of social research as the pursuit of absolute knowledge through the scientific method and the gradual disillusionment with the interpretative view of such research as the generation of socially useful knowledge within particular historical and social contexts. The emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs (Oliver 1992:110).

He contends that oppression cannot be addressed in an objective or scientific manner; it warrants an openly partisan and politically committed approach and following Becker (1967), should take the side of the oppressed. He calls for 'what has variously been called critical inquiry, praxis or emancipatory research' (1992:107). Research must confront disability and must be located in the social model of disability, rejecting impairment as the root cause of disabled people's problems. Stone and Priestley (1996) have identified six core principles which they see as characterising this emancipatory research paradigm:

1. the adoption of the social model of disability as the ontological and epistemological basis for research production;
2. the surrender to falsely premised claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation;
3. the willingness only to undertake research where it will be of some benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;
4. the devolution of control over research production to ensure full accountability to disabled people and their organisations;
5. the ability to give voice to the personal whilst endeavouring to collectivise the commonality of disabling experiences and barriers; and
6. the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

Finklestein (1996) has called this an 'outside-in' approach, in which the focus of research and political activity is on 'dismantling the real disabling barriers 'out there'' (p34). He argues that the approaches of, for example Morris (1991, 1996) and Shakespeare et al (1996) by focusing

² It is important to note that Oliver's attack is an attack on both positivist and interpretivist research.

on the experience of disabled people is a 'discredited and sterile approach to understanding and changing the world' (Finklestein 1996;34). It diverts attention from the causes of disablement, confining political action to personal experience and preventing disabled people from forming alliances with other oppressed groups (p36).

Disability research, within this paradigm, implies that disabled people become more than mere participants (Zarb 1992), they must influence the design, the content, the conduct and the dissemination of the research (Priestley 1997). Barnes (1996) makes clear that researchers on disability have a duty to the disability movement; to confront and overcome oppression. As Bury (1996), in a repost to Barnes' position puts it, 'you are either for us or against us' (p246). Research projects that attempt an emancipatory paradigm face a number of methodological difficulties (Stone and Priestley 1996), namely: the tensions created by a need to surrender control to the research participants whilst maintaining academic credibility; the uneasy relationship that may develop between the researcher's expertise and disabled people's expertise; and, the problem of prioritising the social model of disability when research participants may not ascribe to that 'oppression theory'.

Oliver (1997;25) has recently argued that one cannot 'do' emancipatory research, but it is the role of that research that must be emancipatory. For social model theorists such as Finklestein, Barnes and Oliver, Utopia, namely the removal of disability, can be created by changing consciousness, replacing individualistic models of disability with the social model. Theory, following Marx, becomes transformative: as disabled people adopt the social model, their understanding of themselves, of their position in society, of the institutions they access are altered; disabled people are thus transformed into political activists. Research must therefore seek to document discrimination, making disabled people aware that the problems they face are the outcome of the way that society is organised to exclude them. Barnes' *Disabled People in Britain and Discrimination* (1991) exemplifies this approach. The approach closely mirrors that of Freire, the knowledge generated by research aims to redefine disabled people as subjects, allowing them to transform and recreate their world:

The pedagogy of the oppressed [is] a pedagogy which must be forged with , not for, the oppressed (be they individuals or whole peoples) in the incessant struggle to regain their humanity. This pedagogy makes oppression and its causes objects of reflection by the oppressed, and from that reflection will come liberation. (Freire 1982:25)

This is not to suggest that these writers have reached their position without documenting the experiences of disabled people. Indeed the work by Oliver et al (1988) Zarb and Oliver (1993)

and Barnes (1990) explicitly draws on the experiences of disabled people. As Zarb and Oliver write in their report on ageing with a disability:

.....it is impossible to develop appropriate policies and support services without an awareness of, and a sensitivity to people's subjective experiences of ageing with a disability (1993:32)

However, Oliver (1997) in his recent paper on emancipatory research, whilst acknowledging that research into disablement must provide a description of the experience of disablement, argues that this experience must be presented in a manner that 'redefines the problem of disability away from it being an individual or welfare one, transforming it into a political one' (p21). Experience is to be limited to disablement, not impairment. Individual experience of impairment is to be avoided because '...the collectivising of experiences of impairment is a much more difficult task than collectivising the experiences of disability' (1996a:51). Oliver and others, by rejecting individual accounts of impairment, directly focus on political action; so Vasey writes:

If a person's physical pain is the reason they are unhappy then there is nothing the disability movement can do about it. All that BCODP can do is facilitate the politicisation of people around these issues. Of course this politicisation is fairly difficult to make practical progress with - much easier to achieve anti-discrimination legislation than a total review of how society regards death and dying I imagine. This might explain why these subjects haven't been made a priority but their day will come (Vasey 1992:43)

Research into disability must therefore be seen as part of an attempt to foster a critical attitude by disabled people towards a disabling society. The social model is a means to provide the theory of change, contributing to the transformation of a mass of disabled people into a politicised grouping whose personal discontents will be translated into a public struggle.

Researching Impairment

Critiques of the disability studies research paradigm are numerous, both from within the disability movement (for example Crow 1996; French 1993; Morris 1991, 1993, 1996; Shakespeare 1997; Corker 1998, Thomas 1999) and beyond (for example Bury 1997; Pinder 1997; Williams 1997). It is the critiques from within the disability movement that are discussed here.

Jenny Morris was one of the first disabled feminists to openly criticise the social model approach. In her writings she clearly makes the case for an acknowledgement of the personal and the experiential. For example she writes:

..there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are *entirely* socially created. While environmental barriers and societal attitudes are a crucial part of our experience of disability - and do indeed disable us - to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying. A feminist perspective can help redress this, and in so doing give voice to the experience of both disabled man and disabled women (Morris 1991;10 emphasis in original)

Morris (1991;1993a;1996) argues that this denial of experience, and in particular the experience of impairment, has led to an under theorising around issues such as gender. For example, she argues that Oliver et al's (1988) study on spinally cord injured men not only treated the male as the general, but also failed to consider gender. So she writes:

..not only is the research inadequate in that it fails to recognise that the work experiences, financial consequences, family relationships, and so on, described are particular to men but also there is no consideration of how gender as a social construct gives particular meaning to these areas of experience for the men in the study. (Morris 1993a;90)

Morris, and other disabled feminists, argue that unless the experiences of disabled people are documented, non-disabled people will be unable to develop any shared understanding of what it is to be disabled. This denial of the reality of disability is as oppressive as any social, environmental or cultural barrier. They, following the old feminist dictum, argue a need to make the personal political. Indeed Morris (1993b) argues that male advocates of the social model 'have been making the personal political in the sense that they have insisted that what appears to be an individual experience of disability is in fact socially constructed' (p68). The politicisation of disability denies any experience of impairment and of the body. Research, according to Morris must 'analyse the personal experience of our bodies and of our minds for if we don't impose our own definitions and perspectives then the non-disabled will continue to do it for us in ways which alienate and disempower us' (1996;14). Thus, following Morris' argument, research into the experience of being a disabled person can in itself be emancipatory. Crow (1996) also makes a similar point, arguing that only through the development of methods that enable the integration of impairment with disablement will disabled people, at both an individual and collective level, be able to fully challenge disability.

In her later work, Morris goes further and argues:

There was a concern amongst some disabled women that the way our experience was being politicised didn't leave much room for acknowledging our experience of our bodies; that too often there wasn't room for talking about the experience of impairment, that a lot of us feel pressurised into just focussing on disability, just focussing on social barriers. For many this feels a very dangerous thing to say, in that we feel it makes us vulnerable to non-disabled people turning round and saying - 'there you are then, we always knew that your lives were awful because of illness or incapacity, we always knew what a tragedy it is (Morris 1996;13)

However, as Thomas (1999) has pointed out, the debate between Morris and other disabled feminists and Oliver and other social model theorists is not really about the place of experience in research, but about whether research should focus on impairment or disablement. That is, Morris is arguing for a position in which the impact of impairment is put into the foreground, whilst Oliver argues for a focus on the material, social and political. Thomas (1999; 74) suggests that this debate arises as a result of a public/private split. Social model theorists suggest that the private should remain private and should not be the domain of disability studies. For example, Oliver (1996; 3) argues that 'there are things which are and should remain private'. This strategy, as Thomas argues, is problematic:

...[the] consequence of leaving aspects of social life and social oppression which are so keenly felt by many disabled people (to do with self esteem, interpersonal relationships, sexuality, family life and so on) allows 'open season' to psychologists and others who would not hesitate to apply the individualistic/personal tragedy model to these issues (1999;74)

This position is supported by, among others, Shakespeare et al (1996;6) and Shakespeare (1997), who, in their work on sexuality and disability, make the point that this denial of experience has led to a bracketing of personal issues within the disability studies literature. They suggest that this absence is in part driven by a backlash to the individualising medical tragedy model, leading to a 'desire to move away from individual lives towards structural and political analysis of the discrimination faced by disabled people' (p6-7). Public issues, such as access, employment and discrimination become the focus of much research, whilst little is known about the private lives of disabled people. Consequentially, research can be inhibited (Shakespeare 1997).

The danger in this approach is, however, that personal experience becomes limited to the personal experience of having an illness or impairment (Thomas 1999). Whilst, for example, Morris (1991) clearly documents the experience of disablement, Crow (1996) seems to confine her writings to impairment and its effects. Through her approach she runs the danger of reinforcing the idea that impairment lies at the root of the problems faced by disabled people, a concern that she herself acknowledges (1996; 71).

Capturing Experience

It appears, therefore, that there are two different approaches to experience within disability studies literature. On the one hand, there are social model theorists such as Oliver and Barnes, who see any attempt to uncover disabled people's experiences as individualistic unless it is read through the social model. The *Fundamental Principles of Disablement* (UPIAS 1976) make this position clear:

We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in is the ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way society is organised to exclude us (1976; 4-5)

On the other hand are those, such as Morris and French, who seek to adopt a 'feminist' perspective and have reified experience, rather than situating it as a discursive product or viewing it in relation to power. Crucially, however, Morris and other feminists appear to view experience only as the experience of having an impairment and the impact that impairment has on the personal (Thomas 1999). There is little attempt to analyse or explore the day to day life of disabled people as people.

Notwithstanding this, if the points made by Morris (1996), Crow (1996), Shakespeare (1997) and Shakespeare et al (1996) among others, about the importance of experience are accepted, the issue becomes, how is experience to be captured. In many of these texts experience is presented as an unproblematic issue. That is ontologically and epistemologically it is assumed that there is a real world out there, one that can be captured and reproduced through inductive analysis. It is the collection, the analysis, the interpretation and the representation of data that are used to provide a picture of the experience of having an impairment that many in disability studies are troubled by, particularly social model theorists. This is by no means a new critique and extends back to Paul Hunt's (1981) concerns about the report by Miller and Gwynne (1972) into life in the La Court Cheshire Home. In this report the experiences of the residents as perceived by the researchers did not accord with the experiences of the residents as perceived by the residents themselves (Hunt 1981). This raises the question of whether it is possible to

probe and reveal lived experience and is what people say an accurate reflection of their lived experience. It is to this issue that this chapter now turns.

Skeggs (1995) argues that the representation of experience is mediated on two fronts. First, those who recount their experiences to researchers mediate their stories, they re-interpret what happened in the light of prior or subsequent experiences. Similarly, researchers interpret these accounts through their own experiences. Gerts puts this neatly:

What we call our data are really our own constructions of other people's constructions of what they and their compatriots are up to (1973;9)

This is what Denzin (1997) has termed the 'crises of representation'; that is, is it possible to capture lived experience, or is the experience merely created in the written text? Through analysis of interview transcripts, or other data, social scientists can claim that the picture they are presenting is a 'real' picture, and that the image they are creating is a 'real' representation of the world under analysis. The status, or the value, given to any representation of experience is the product of the writer, not the research informant (Clandinin and Connelly 1994). So Denzin writes:

The subject is a textual construction because the real flesh and blood person is always translated into either an analytic subject as a social type or a textual subject who speaks from the author's pages. (1997;5)

Experience is always already social; we can have no independent access to nature, whether bodily or external, which is not already structured by language (as Derrida, Wittgenstein and others have argued). Describing somebody as impaired or disabled are in themselves a social construction, as is any concept built on the notion of a 'disabled experience'. These categories, and those such as gender, class, 'race'/ethnicity are not essences (Stanley and Wise 1993;11). As Fuss writes:

Bodily experiences may seem self-evident and immediately perceptible but they are always socially mediated....we need to be extremely wary of the temptation to make substantive claims on the basis of the so called authenticity of our experience. (1989;25)

Morris (1991) and Crow (1996) base their ideas on the assumption that the informants' answers are always the most accurate, that they have revealed their lived experience and that their word is all. Talk equals lived experience and its representation. Yet, the crisis of representation leaves us with an ambivalence between wanting to foreground and give credence

to experience, whilst at the same time recognising that that experience is overlaid by broader structures and meanings that individuals may not be aware of. At the root of this dilemma is the relationship between objective structures and subjective experience. The assumption that through documenting experience we can uncover how these structures impact on the social world assumes that these individuals have not been damaged by their social experiences (Flax 1990). It is this point that Oliver (1997) uses when, as discussed above, he cautions against an analysis of disablement based on experience. His argument is that we already know that disabled people live in a world that is organised in such a way so as to exclude them, and if we are to interpret what they say, then we must do so with this in mind. This implies that whatever explanation somebody gives to describe their experience, it must be read through the social model. Even if they themselves do not recognise that they are oppressed, researchers must. Implicitly, this endorses a notion of 'false consciousness', if a disabled person describes themselves as disabled because of their impairment and refuses to endorse a social model approach, then they are, simply, wrong. Further, it suggests that researchers, provided they support the social model, know best.

Interestingly, Oliver's neo-Marxist critique of experience concords with that of post-structuralists such as Fuss (1989) and Richardson (1994). They all seem to argue that theory can not be built on the basis of experience. This rejection of experience as a starting point for theory has not gone unchallenged in feminist literature (Thomas 1999). Stanley and Wise (1993) make the case for an approach which explores in detail why and how people construct their realities. Through looking at the 'personal', through exploring experience and locating that within the structural and cultural, oppression and emancipation can be more clearly understood. Documenting and representing experience therefore becomes a balancing act that recognises the various issues at play, that doesn't render individuals invisible, or make objects of them, but doesn't deny the place of structure. As Harraway writes:

I think my problem, and 'our ' problem is how to have simultaneously an account of radical historical contingency for all knowledge claims and knowing subjects....and a no-nonsense commitment to faithful accounts of a real world (Harraway 1988;579)

All accounts are therefore partial, none of them are wrong but none of them are complete. However, it is only by focussing on the life world, the world as it is experienced, the world people take for granted, that we can learn how social objects are made meaningful. As Schutz argues: 'The safe guarding of the subjective point of view is the only but sufficient guarantee that the world of social reality will not be replaced by a fictional non-existent world constructed by the scientific observer' (1964;8).

A further problem that Denzin (1997) identifies in relation to qualitative research and the documentation of experience is what he terms a 'Crisis of Legitimation' (p7). This crisis of legitimation arises from cries for validity, for reliability, for objectivity, for triangulation and grounding. Such processes serve to legitimate a text's authority. Silverman (1993;145) places 'reliability' and 'validity' as the two central concepts of this rigour, .

Reliability

Reliability is the extent to which two independent observers would reach the same conclusions from the same data or the by the same observer on different occasions (Hammersley 1992). Hammersley (1992) argues that reliability can be assured, it is presumed, by following set criteria, for example; using carefully recorded, extensive and standardised field notes; pre-testing interview schedules to ensure that each respondent understands the questions in the same way; and using standard conventions for transcriptions.

Validity

Validity is both internal, the degree to which findings correctly map the phenomenon in question and external, the degree to which findings can be generalised to other settings. It is what both Hammersley (1990;57) and Silverman (2000; 175) call 'truth'.

Clearly, the use of the word 'truth' is problematic, so how can one achieve validity while recognising multiple realities? If reliability and validity are to be the criteria on which the legitimacy of a project are to be judged, research participants are required to act as rational subjects and not to contradict themselves . The assumption is that individuals hold fast to their world view and that they are embedded in a fixed social world. By employing a structured, pre-tested interview technique meaning can be universalised.

Whilst calls for validity came originally from positivists, a perspective that argues for the development of universal laws (Altheide and Johnson 1994), some, working within the qualitative paradigm, for example Silverman (1993, 2000) and Hammersley (1990, 1992) have suggested the adoption of similar criteria for assessing quality. They recognise that there is a difference between qualitative and quantitative research, but propose new criteria for quality based on the idea of validity and reliability. They argue that there is a reality that can be known, what Hammersley terms a subtle form of realism:

This subtle realism retains from naive realism the idea that research investigates independent, knowable phenomena. But it breaks with it in denying that we have direct access to those phenomena, in accepting that we must always rely on cultural assumptions, and in denying that our aim is to reproduce social phenomena in some

way that is uniquely appropriate to them. Obversley subtle realism shares with scepticism and relativism a notion that all knowledge is based on assumptions and purposes and is a human construction, but it rejects these positions abandonment of the regulative idea of independent and knowable phenomena. Perhaps most important of all, subtle realism is distinct from both naive realism and relativism in its rejection of the notion that knowledge must be defined as beliefs whose validity is known with certainty (1992;52)

He proposes that 'An account is valid or true if it represents accurately some feature of the phenomena that is intended to describe, explain or theorise' (p69). He identifies four criteria for quality; plausibility, relevance, credibility and importance of the topic. Silverman (1993;166) suggests that we can get nearer to this 'subtle form of realism' by comparing a qualitative sample with a larger sample to establish a sense of representation, through hypothesis testing (using the constant comparative method similar to that of Glaser and Strauss (1967)), and the use of counting measures. These criteria have been drawn up in response to critics who argue that qualitative research, because of its reflexive character, is partisan, incomplete and biased towards the views of the researcher (Altheide and Johnson 1994;487).

These attempts to establish a set of rules through which a reality that exists outside of the text can be documented are a claim to power (Denzin 1997) within the academic community, so Hammersley writes:

In my view, the immediate audience for research must be the research community, even though the ultimate aim is to produce information that is of value to others. Therefore communications to policy-makers from researchers should draw on multiple studies and on the necessarily provisional conclusions of the research community about their validity, rather than reporting the outcome of a particular piece of research. (Hammersley 1992;132)

Hammersley is therefore arguing that by the application of theory, validation emerges, and that the most competent judges of the validity of a particular project are academics, not the members of whatever group is being studied (Stanley 1993). He appears, in effect, to be calling for some form of objectivity in assessing the legitimacy of a particular project.

For postmodernists the concept of validity is rejected (Silverman 1993). The actual practice of research, the interviewing and the observation, produce understandings that are situated (Denzin 1997). They cannot be generalised, they are local; social reality is fluid, there is not one reality, there are multiple realities. All realities are constituted through discourse and power and therefore any attempt to measure reality is meaningless. As Richardson writes:

The core of postmodernism is the doubt that any method or theory, discourse or genre, tradition or novelty, has a universal and general claim as the 'right' or privileged form of authoritative knowledge.....The post-modernist concept of doubt distrusts all methods equally (Richardson 1994;517-518)

All methods are therefore equally valid and equally suspect. There is no crisis of legitimacy, the qualitative researcher is no longer bound by any criteria. Equal status is accorded to, for example, 'fly on the wall' television documentaries and sociological or anthropological projects. If this is accepted, and social science consists of mere accounts, the question becomes 'Why should we bother to read them?' (Silverman 1993;155).

Writers who adopt what Denzin (1997) terms a critical post-structuralist position recognise a need for criteria for assessing quality, but argue that any such criteria must be different to the positivist criteria of validity and reliability. The concepts of validity and reliability become replaced by the idea of legitimacy and authority and, in so doing the reasoning behind such criteria become apparent. As Denzin states 'The unmasking of validity as authority now exposes the heart of the argument. If validity is gone, values and politics, not objective epistemology, govern science' (1997;9). All texts are stripped of external claims to authority and the legitimacy of research is evaluated on the basis of the extent to which research empowers or emancipates. A moral and ethical responsibility therefore becomes attached to the production of knowledge. Analysis is focused on the power and discourses that repress (for example class, gender, law, ethnicity, disability). However, the rejection of meta-narratives (Lyotard 1984) suggests that politics must be local, contingent and piecemeal; the fact that repression is produced within discourse means that such an analysis must be historical and contextualised within specific discursive formations and practices rather than an attempt to bring an end to all repression. It is about making people more aware and tolerant of issues of difference, ambiguity, uncertainty and conflict (Seidman 1994). In relation to disability, the totalising analysis of Oliver and others is therefore rejected.

The question now becomes whose morals, whose ethics, whose politics? Who are to be the judges of what is emancipatory? Hawkins (1993), for example argues that her 'pathographies', or personal illness narratives, allow people to come to terms with their 'traumatic experience' (p10), a similar approach is taken by Frank (1995) and Kleinman (1988). Sociology therefore becomes the confessional; through writing about it and putting it into words 'triumph over the alienation created by the institutional appropriation of the body through an official medical discourse that interpolates the body in official medical detail but denies the voice of the *lived* body' (Frank 1996;62) is achieved. These are little more than what Hunt (1966) termed 'sympathetic biography', the role of sociology as public educator

(Seidman 1994) becomes that of sociology as public confessional. Sociologists, it appears, must stand alongside Oprah Winfrey, Rikki Lake and Esther Ranson. These approaches merely serve to reinforce the idea of the 'disability as tragedy' syndrome. They fail to analyse the social, cultural and economic forces that structure the lives of disabled people. Indeed as Radley (1995) argues, these narratives can themselves become disciplining.

In the work of Shakespeare et al (1996) on sexuality and disability a completely different level of politics emerges. This work is not only about self validation for disabled people, it also challenges non-disabled people's values, demanding that they accept disabled people as sexual and emotional agents in their own right. Further it positions sexuality and relationships within the remit of the disability movement, doing so from a civil rights perspective. As they argue:

We can talk about sex. We can *have* sex - we are entitled to have sex and find love. We *do* face oppression, abuse and prejudice, but we can fight back and we can demand support and the place to heal. (Shakespeare et al 1996;207)

The aim of social science is therefore to make people aware of new possibilities and to present the multiple viewpoints that emerge from data. It is through the researcher's own commitments and politics that the nature of phenomena are investigated and reported, and it is the role of the researcher to make clear their own political and moral standpoint. Denzin, drawing on the writings of Joyce, suggests a need to develop a new language for ethnography:

Any new language, of course, will be the language of a new sensibility, a new reflexivity. This will be a language that refuses the old categories, that reflexively and parasitically, in a rhizomatic manner (Deleuze and Guattari 1987, Chapter 1) charts its own course against Joyce's repressive structures of history, economy, race, class, gender. This new language, post-structural to the core, will be personal, emotional, biographically specific and minimalist in its use of theoretical terms. It will allow ordinary people to speak out and to articulate the interpretive theories that they use to make sense of their lives. (1997;26)

Research must therefore become pragmatic, arguments become circular and ambiguous (Seidman 1994). All research and research findings are contestable. There is no attempt at closure. There is a recognition that we can't solve problems, but that research is open to dichotomies and contradictions. Whilst there are dangers in this approach of relativism and idealism, of reality being reduced to meaning and language with no link to anything outside of language (Hughes and Sharrock 1997) it does open up a possibility of individuality, democracy

and choice (Seidman 1994). It is an imprecise approach but still one that opens up possibilities. As Wittgenstein writes:

.....but isn't it an inexact explanation?- Yes; why shouldn't we call it 'inexact'? Only let us understand what 'inexact' means. For it does not mean unusable (Wittgenstein, 1958;14)

Insider or Outsider

Objectivity, the extent to which findings are free from bias, presumes a researcher who is disembodied, one who is not embedded in the social world of those who are being researched (Denzin 1997). It implies that research is done from the outside looking in rather than from the inside looking out. As a disabled person writing on disability this is a position that I can neither obtain nor would I wish to. Given what has been previously argued it is important that my own political, academic and cultural prejudices emerge through this writing, and also how these were altered through the research process (Davis et al 2000). This is reflexivity. As a disabled person I am constantly reminded of the discrimination and prejudice experienced by disabled people. Barely a day goes by without somebody commenting on my impairment, asking me what is wrong with my leg or offering help where none is needed. In this research I was both researcher and instrument of research, building a theory and an observer and participant in the research setting. On entering the research field I brought with me what Peters (1995) terms 'baggage'.

This baggage is the product of both my own personal experiences of disability and experience gained as an activist in the disability movement. I have seen the inequalities that disabled people face and have felt the prejudice. This is not to suggest that my experiences mirror those of the participants in the study, or that being a disabled person gave me a unique perspective that would not be available to a non-disabled person. Such a claim would suggest that disability is in itself an essential characteristic and that having this characteristic I have privileged access to the experiences of that group. This is not only spurious, but also dangerous (Hammersley 1995;52-53). My experiences as a white, middle class, heterosexual, English male who acquired an impairment in my early thirties are very different from many other disabled people. For example Yvonne, a participant in this study, is a white, working class, Scottish, lesbian in her early twenties who has a congenital impairment and Jay, also a participant, is a heterosexual male from the Indian sub-continent who acquired an impairment in his childhood; we have little in common in our life experiences outside of the fact that we are all labelled as disabled people. However, it would be wrong to suggest that being a disabled person did not influence me in this study, both through aiding the recruitment of participants and in the interviews themselves as well as provoking my interest in the topic in the first place. Organisations of disabled people, many of which I had had contact with prior to carrying out

this work, commented on how they felt more relaxed about circulating my request for volunteers because the work was being done by a disabled person who was known to them and many of the participants commented on the fact that they felt more comfortable talking to a disabled person. Being disabled clearly helped me in developing trust and rapport with the participants.

There is also a downside to researching what some may see as shared social experiences, as Weston writes:

Presumptions of a common frame of reference and shared identity can also complicate the anthropologists task by leaving cultural notions implicit, making her (sic) work to get people to state, explain, and situate the obvious. To study one's own culture involves a process of making the familiar strange (Weston 1991;14)

Whilst Weston describes gays and lesbians as a cultural grouping, a term I would feel uncomfortable with if applied to disabled people, I share her thoughts. This was something that was particularly accentuated when talking to people who had had a spinal cord injury. There is only one hospital in Scotland that deals with people with spinal injury and consequently we all shared the same consultant, knew the same physiotherapists and nurses and so on. It was therefore difficult for me at times to get the participants to elaborate on what they meant. Indeed, by asking them to be more specific I sometimes ran the risk of othering myself from them; by asking them to explain something that they might have felt I should have known, and in most cases did, there was a danger that I could have lost any trust placed in me because of any perceived insider status. However, all this can be, and was used, reflexively.

As the researcher, I am the agent of research. My role is that of interpretation. This interpretation is not an attempt to describe some form of social reality. It is an endeavor to challenge social injustice (Kincheloe and McLaren 1994). Whilst as a sociologist I have difficulties with the social model, on a political level the social model makes sense. This work is driven by a personal commitment to disability politics, by a belief in civil rights and citizenship. To paraphrase Campbell (1995;229), the participants in this study are not to be seen as a source of intellectual enjoyment, a means through which I can gain academic cache. What I see as important is that there is action to redress the injustices. Research is more than increasing knowledge. Oliver (1992, 1997) is therefore correct when he argues that research on disability must come from an emancipatory paradigm. However, it is his insistence on the collectivisation of research, the idea of meta-narratives that is deeply problematic. Whilst I was clear, when I started this research, of my own ideological and epistemological positions and aware of my own political and personal baggage, I was ready to change these assumptions in the light of emerging themes from the research. As Kincheloe and McLaren argue 'Stimulus

for change may come from the critical researcher's recognition that such assumptions are not leading to emancipatory actions' (1994;140). Oliver, and others, by wedding themselves firmly to the social model deny that research may be an organic process. By reifying a particular structural relationship, and failing to see the complexity of the social world, its unpredictability is lost in a claim to universality.

Social model theorists continue to represent disability in a way that may be contradictory to the views of many disabled people. By analysing disability through the lens of the social model they run the risk of failing to see the experiences of disabled people as they themselves see them. This approach, far from empowering the individual, can reinforce the power relations of the research process (Kinchloe and MacLaren 1994). What Finklestein (1996) calls an 'inside-out' perspective can only truly be achieved if the researcher is open to new ideas, to critically reappraise his/her epistemology in the light of the emerging data and not be tied to sterile dogma.

Research Method

The research question now becomes one of methodology; how can I, as a researcher, go about finding out about the experiences of disabled people, the embeddedness of their daily lives, how they negotiate their ways through their social worlds as embodied subjects? A method is needed that firmly places their experiences within culture and structure without reifying either. This suggests that the work must be biographical, personal and historical, that it must be contextualised and situated within the structures that create the discourses that serve to shape an individual's life. As Wright-Mills notes 'Neither the life of an individual nor the history of a society can be understood without understanding both' (1959;9).

Whilst recognising the diversity of method in the qualitative canon this research proceeded along a broadly interpretivist line, one that has a concern for the actors point of view, that seeks to explore what Denzin (1989;20) terms the 'ideographic' or emic perspective. This assumes that each individual case is unique, the interaction is shaped by the individuals in it and this interaction is located within a particular historical and contextual structure. Interpretivist thinking has grown out of the German intellectual tradition of hermeneutics and the phenomenology of Alfred Schutz (Schwandt 1994). When I first began this research I was particularly influenced by Plummer's (1995) *Telling Sexual Stories* and Connel's (1987) *Gender and Power*.

Plummer's work draws on the symbolic interactionist tradition of Mead and Blumer, the basic tenets of which have been discussed earlier. Plummer, in his description of what he describes as a sociology of stories, states:

Isolated individuals and abstracted societies are there none. We human beings are social world makers, though we do not make our own social worlds in conditions of our own choosing. Through symbols and languages, we are able to reflect upon ourselves and we cannot but help acting in, on and through the world. We work and worry, love and hate and *all the time we are telling stories* about our past, our present and our future. (1995;20)

It is through joint action, either as the producer of a story, the provoker of a story or the consumer of a story, that *an* understanding of meaning emerges. These meanings are not fixed, but are always shifting.

Connell's work on gender (1989,1995) was also particularly helpful. His approach, rather than focus on ultimate origins or root causes, examines gender relations as a going concern, implying that structures are not pre-given, but historically composed. Through this he develops a practice based approach to the structure of gender relations. However these structures are not ahistorical, and he locates the construction of genders within discursive formations. For Connell, gender is not fixed outside of social interaction, but is constructed in interaction at both the micro and macro level. His work is also grounded in an idea of social justice. From Connell's work I took the concept that the idea of a non-disabled person and disabled person is relational, the category of disabled person only has meaning as a social demarcation. Disabled people are the product of practice, structured by interactions with individuals and institutions. They are historical and their defining and categorising is a political process (see also Stone 1984). Through analysing micro interactions, whilst, at the same time, taking account of the macro, many of the problems of the interpretivist perspective, highlighted in chapters one and two, can be overcome.

Interviews were used as the method for accessing disabled people's views on a variety of subjects. Interviews are one of the most common and potent tools available to sociologists (Fontana and Frey 1994). Through the use of lengthy, in-depth interviews it is possible to come to an understanding of the meanings that underpin the lives of people, their routines, feelings and behaviours (Rubin and Rubin 1995), and to find out what is on and in a person's mind (Patton 1990). The format of the interviews is discussed later in this chapter.

Research Participants

I wanted to recruit participants from as broad a base as possible. This was not an attempt to gain a representative sample but for the development of theory (Glaser and Strauss 1967) which would allow for a wider understanding of the experience of disablement and impairment. To this end, I tried to include people with a wide variety of impairments, people who were parents, who were single, who were cohabiting, people who were working, people who were unemployed, people who were active in the disabled people's movement, people who had so called 'progressive' and 'static' conditions, gays and lesbians and people from different ethnic groupings. I managed to meet most of these requirements but was only able to recruit one person from an ethnic minority. Participants in the study were recruited from organisations of, and for disabled people (Lothian Coalition of Disabled People, Lothian Centre for Independent Living, Disabled of Craigmiller, Scottish Spinal Cord Injuries Association, Milan), housing associations (Margaret Blackwood, Edinvar, Freespace Housing, The Thistle Foundation and Horizon Housing) and disabled sports and social clubs. In the end 28 people, 14 men and 14 women, who were all volunteers, enlisted in the study. They were all informed about the nature of the work, the structure of the interviews, the funding organisation and the potential use of the work. They have all been kept informed of how the work has progressed and because of the multi-interview format that was adopted in this study, were able to comment on, and refute my initial analyses of both their own contribution and those of others.

The sample included people with cerebral palsy, multiple sclerosis, spinal cord injury, FSH muscular dystrophy, spina bifida, rheumatoid arthritis, polio, muscular ataxia, hydrocephalus and other unnamed neuromuscular degenerative conditions. Informants' impairments are not identified unless it is necessary to contextualise their comments. Sheila, Lucy, Anne, Bert, Simon, and Collette were under 25, Arnie, Archie, Deirdre, Joyce, Keiron, Leslie, Mark, Ruth and Tommy were aged between 25 and 34 years old, Drew, Harry, John, Caroline and Stella were between 35 and 44, Holly, Javid, John, Jane, Marion and Stewart were between 45 and 54 and Moira and Agnes were aged between 54 and 59. Sheila, Collette, Keiron, Leslie, Mark, Stella and Drew all worked on either a full time or part-time basis; none of the others worked. All the names given are, of course, fictitious and at times some data has been changed to ensure anonymity.

Structure of Interviews

The interview format followed a multi-interview, in-depth, semistructured arrangement based on the approach of Backett (1991). Each participant was interviewed twice over a 12 month period. All the interviews, except one, took place in the participants' home (one participant,

Joyce, asked to be interviewed in the University because she wanted to see what the University was like). All interviews were taped and transcribed, however four of the participants had speech impairments that precluded the use of a taperecorder. In these interviews I made notes and whilst there are few direct quotes reported from these participants, their views and experiences are, of course, included in the overall analysis.

The topic guide for the first semi-structured interview was drawn up after sensitising work using participants recruited from a similar sample frame to that employed in the study. Subjects that were included in the first topic guide included health, effect of disability on views of health, images of self, others views of self, access and the health services. The topic guide was informed by my own theoretical knowledge of, and interest in, topics such as sociology of the body, medical sociology and health promotion and also the results of the sensitising interviews. The focus on health was, in part driven by the sponsors, the Health Education Board for Scotland, who part funded this project. This guide was not a tightly structured set of questions, but a list of topics that I felt that I wanted to cover. The wording of the questions and the order in which they were asked were altered in the course of the interview, depending on the responses that the participant gave to earlier questions. In this way the topics could be covered in any order and a manner that was in keeping with the flow of the interview. In essence the topic guide was used as a checklist to ensure that the interview covered all the desired areas (Lofland and Lofland 1984). As the studies progressed the topic guides were altered in response to previous answers³. In this way the topic guide was both theoretically and empirically informed.

The topic guide for the second round of the interviews was derived from themes that emerged from the data obtained in the first round. Areas covered included mental health, emotional wellbeing, feelings, quality of life and attitudes to disability/impairment. This interview also looked at the events that the participant believed to have been the most important or significant in the time between the interviews.

The interviews themselves went very smoothly. All the informants made me feel very welcome. In most cases, it was easy to get the informants to talk. Some informants were more verbal than others and the interviews lasted for between 60 and 120 minutes. The multi-interview format allowed a greater rapport to be developed between myself and the participants. For example, one of the informants, Deirdre, told me in the second interview about her history of sexual abuse and how this had affected her view of herself. If the project had been confined to just one interview, such details would have been lost. The informants were much more relaxed in the second interview. They knew what to expect. It also gave the participants time

³ An example of how the interviews developed is given in chapter four.

to reflect on his/her responses to the earlier interview. Further, the multi-interview format also provided me with an opportunity for inductive and recursive analysis of the data. Emergent themes were able to be explored further; and individually salient issues were able to be treated in depth in subsequent interviews. Many of the participants told me how much they valued this, how they liked to hear both what I thought about their earlier comments and what other people had said.

Analysis

Analysis of the data was to be based on the ideas of Lofland and Lofland (1994). Put simply Lofland and Lofland's approach to qualitative data analysis is based on the emergence of theory from data. It involves inductive, comparative analysis of the data through which theory is developed. Immediately after the interview I listened to the tapes and made notes on what I thought had been the most important issues raised and wrote field notes on how I felt that the interview had gone, checking to see how the participants had responded to various questions, trying to ensure that I had avoided the use of leading questions. In other words I tried to check on any errors that I might have made so that they could be corrected in future interviews. Through this formative analysis I was able to make an early note of patterns and themes that emerged from the data. This interim analysis was integral to the research process and laid the foundations for latter and final analysis. The interim analysis allowed me to make sense of the data, to group the participants' responses and to make an early attempt at identifying emergent themes. I was trying to find out what was going on and how things were proceeding.

Initial analysis was performed using NUD.IST computer package for handling qualitative data. This allowed information to be stored in a tree-structured index system. I read through the interviews, coding the data in a similar manner to that described by Silverman (1993). The categories evolved as more and more transcripts were analysed. By using this coding tree I was hoping to be able to identify patterns, breaking the data down into manageable units and regrouping this data as emergent themes (Atkinson 1992). However, it soon became clear that whilst this method was useful in gaining an entree into the data, I was losing any sense of biography of the participants. I was seeing their comments as independent bits of information, and failing to contextualise much of what they were saying. My approach had become technical. This problem was exacerbated by the ease with which new categories could be created within NUD.IST and when I came to analyse the second round of interviews I used much broader categories. I was also aware of what Atkinson (1992) warns as the dangers of missing uncategorised data. The technique had started to drive the theory that was emerging, rather than the data doing so.

To redress this effect, I wrote full biographies of the participants, describing what they said, trying to avoid interpretations (Dingwell in Silverman 1993;39). These biographies included

notes on the interview itself, how I felt they went, descriptions of the participants housing, the arrangements of the room and so on, attempting to create what Denzin (1989;83) calls 'thick description'. By contextualising the interview, the accounts became more fluid; meanings, actions and feelings were given prominence. However, as Denzin (1989) points out, these descriptions were not mere descriptions, they also involved interpretation. That is, in deciding what I felt was important and should be included in the description involved interpretation. They were not just a presentation of facts, but were an attempt to grasp what I saw as the salient and significant details in the participants' responses. This helped with the analytical process.

Through writing these 'biographies' I was able to better understand the lives of the informants, to become immersed in their lives through the text and to avoid seeing them as a collection of disembodied quotes that corresponded to emerging themes. I found myself constantly thinking about what the participants had said, trying to interpret their ideas, making sense of their experiences and locating these experiences within the social context in which they were situated. It is what Denzin (1989; 116) describes as a 'process of progressively defining and interpreting the phenomenon to be understood'. Through the process of coding, description and interpretation of the data the various perspectives of the research participants emerge. The emergent meanings were able to be contextualised and situated within specific historical and discursive formations. At the same time I was able to look for emerging patterns in the participants social worlds, the generic, though not fixed elements that made up the individuals' social lives. I felt that my analysis and interpretation of the data was therefore embedded in the social worlds of the participants and not the product of what Mills (1959) terms Grand Theory.

Disability arises through social practice and is structured by relations. Disability is historical and its making and remaking is a political process. There is no entity called 'disability', and when research on disability issues is carried out theory and method are obviously interlinked. A materialist analysis, for example, may give knowledge of macro processes that generate inequality but may not allow an analysis of the practical routines of social life, how the macro is played out in the micro. On the other hand, a micro analysis, with its focus on individual perspectives, can ignore hierarchical issues. Connell (1995;44) argues that critical social science must operate within an 'ethical baseline' and that at the root of this baseline should be a commitment to social justice. Social justice, in the case of disability, refers to justice in relations between disabled and non-disabled people. Disability, and our knowledge of disability, has an inherently political character. Social processes at the macro level do not occur in a vacuum they are situated and structured. Similarly, social action at the micro level constitutes and re-constitutes these social processes. This suggests that research on disability must investigate at both the macro and the micro, examining social actions whilst locating them within social processes. That is what this thesis attempts.

It is to the actual analysis of the data that this thesis now moves. The four main themes that emerged from this analysis of the data are; how the informants experienced impairment, the experience of disablement; identity and how that identity was maintained. The first theme, the body, was, in the main, driven by a pre-conceived interest in sociology of the body. The second theme, disablement emerged as a central category from the data. All of the informants talked about their interaction with other, non-disabled people and the problems that this could cause. Having explored this experience of disablement I became interested in what effect this had on their views about themselves and how they maintained those views, especially in light of their views about their body. This forms the basis of chapters six and seven.

Chapter 4

Experiencing Impairment

Introduction¹

This chapter discusses the ways in which the research participants talk about their body or describe actions which pertain to the body. It starts with a description of how the data were collected, the type of questions used and the responses of the informants as I tried to get a sense of the participants 'body as is, or the body-I-am' (Connell 1995), that is the lived embodiment of having a physical impairment and being a disabled person. It then moves on to examine the way that the body disappears or *dys*-appears (Leder 1990), doing so through an exploration of the participants accounts around health. The next section explores how the participants related to their body and the care they took of it. The final section is based around data in which the participants describe how their relationship to their body was affected by their emotions and feelings.

Capturing the Taken-For-Granted

As chapter one and two make clear, before the start of this research, I felt that the lack of an element of physicality was one of the major weaknesses of the social model. I was therefore particularly interested in how the participants talked about their bodies, their relationship to their body and how their body and health were embedded in their social and life world. In this sense, this is not a category that emerged from the data, as the other themes explored in these chapters have, but was one that I set out to examine. However, the method of examining it was not as simple as I thought it would be when I set out on this research. Following sensitising work and the early interviews it soon became clear that the body was not a subject that many people felt comfortable talking about. The reaction of Jane, who was the second person I interviewed clearly shows this:

We're always coming back to this body - is it so unique!

Her response and that of others made it evident that any direct reference to the body was likely to produce a similar response. The participants either thought that I was referring to their impairment and so their answers tended to focus on that particular issue, or they did not understand what I was talking about. It soon became clear to me that we, or at least people in Scotland, do not normally openly talk about bodies; such topics are usually confined to the clinic or to intimate situations. It seems that, whilst much of our everyday talk is embodied,

¹ The discussion on the literature on sociology of the body and the notion of embodiment and the taken-for-grantedness of the body discussed in chapter 3 provides the theoretical framework for this chapter.

direct references to the body are unacceptable. Indeed, Cunningham-Burley and Backett-Milburn (1998) have equated talking about the body in research interviews to asking people to undress in front of you.

I wanted to approach the body and issues of embodiment so as to ascertain the experience of having an impairment both as sensation (experienced in the mind and body), and as experienced in the social. This chapter therefore focuses on the embodied experience of the informants, taking as its starting point the 'taken for grantedness' of the body, so as to ascertain the participants' own ideas about their bodies, their sense of embodiment and their lived experience. I wanted to move away from discussing how the participants made sense of their impairment, rejecting the idea that impairment signified 'trouble', as found in much of the previous research on disability and the body. The body was therefore explored through less direct means. For example, at the start of the second interview I asked the research participants what had been the most important things that had happened to them over the six month period between the interviews; many did not talk about their impairment. They talked about their lives as a process, the changes over time that occurred in their everyday interactions. Keiron, for example told me:

My drama group put on a show in October and so I was busy with that and involved with the rehearsals and aspects of the writing and bits of the performing as well, so that seemed to go very well. And then after that I went to Toronto with a friend of mine.

Deirdre talked about her upcoming marriage and returning to college and the demands that this had placed on her; Joyce about her increasing involvement with a voluntary sector organisation and Bruce talked about how he was developing a new circle of friends after moving into his new house and starting a new course. Others talked about nothing major happening to them. Arnie, for example said 'I've been fit and well, very happy with life', and Tommy said:

It's just as normal, as usual. I am not doing anything different. Not from what I have done before, from the last time I saw you. No. I probably can do a bit more due to the weather and that. I do a lot more here and there but apart from that no.

These accounts are clearly all embodied, in that they describe an active process, a process through which the body is doing. They are not focussed on their impaired body, but on their active body. They are mundane, even boring, everyday accounts, and are certainly not the sort of things that attract the attention of many social scientists. Yet, as Whyte, in his ethnography

of a Scottish town, argues, it is precisely this sort of thing that makes up the everyday world of individuals:

it is striking that the things which most concern people in Cauldmoss on a daily basis were, in terms of mainstream sociological theory, generally considered trivia....for instance the cleanliness of children's clothes, the relative expense of wedding presents, or personal reputation in the village. this was the stuff of status distinctions. Factors deemed to be of sociological importance....occupation, class, voting behaviour, were usually experienced by villagers as the inevitable parameters of their condition, and therefore rather futile to dwell on. Within these bounds they led their lives, exercised by issues that were subject to their influence" (Whyte 1993:7)

In the same way that Whyte suggests that sociological categories are seen as inevitable categories of their condition, so, it could be argued, is impairment. It is this issue that forms the central element of this chapter.

Some, however, did talk about their impairments, but in a way that is less clear cut than simply suggesting that their lives revolved around their relationship with their impairment or their impaired body. Stella told me that she'd had 'a ghastly few months' in that she had been hospitalised and off work for 4 months and had only recently felt fit enough to return to her day to day life. This she felt had been partly due to stress in that she had been 'not quite stressed out but stressed because of major events happening in my life, so it has not been an easy 6 or 7 months'. She was not sure if the illness was linked to her impairment 'the doctors never quite got to the bottom of it but I suspect that some of my illnesses have been related to my body structure which is related to my impairment and some not'. The major stressors in her life were, she felt, not related to her impairment, but to do with the fact that 'things are happening both around me and involving me which meant that I have had to be a key figure in all of it, I have felt indispensable'.

Others, however choose to focus directly on their impairment. Eve, for instance talked about 'the gradual deterioration with the MS' and that she had stopped walking "as much as I used to'. Holly and Caroline also expressed concern about how their MS had progressed. For Agnes and Javid, however, the change had been in the opposite direction. Javid talked about how he was getting 'fitter and fitter, and I'm lucky, I had a holiday which relaxed me a lot', and Agnes, after having her leg amputated, was now able to get out of bed (which she had been unable to leave for six months) and was back to 'running my house and everything'.

In these above examples, by giving the participants space to discuss issues that are not necessarily related to their impairment, a picture of their embodied being emerges and the

participants are free to include their impairment if they wish, rather than forcing them to do so by asking questions that directly relate to the body or their impairment. What is clear from these data and from much that is presented later, is that the body only emerges as an issue when it is brought to participants attention. That is it *dys*-appears, as in the case of those whose condition has worsened or where the participants were involved in activities that brought it to their attention. Importantly, if there is no change, or the change is as expected, then the body remains silent. The changes that make the body appear can also be positive as well as negative. This is something that seems to be neglected in much of the writing on the body and impairment. However, all these actions are still embodied.

The most simple means to access the body and get a sense of the taken-for-grantedness of the body was, I found, through an exploration of the participants' views on health and illness². The theoretical reasoning for such an approach comes from both the work of Cunningham-Burley and Backett-Milburn (1998)³ in their explorations of the body in middle years and the work of Schepper-Hughes and Locke (1987). The latter argue that the production and expression of health and illness arise as a result of the interaction between the individual, the social and the body politic. If this is accepted, it should therefore follow that inquiry into how the participants formulated understandings of health and illness provides an avenue through which the participants sense of embodiment, both at a personal level and, its embeddedness within the wider social and cultural environment, can be explored.

Healthy or Unhealthy/Disembodied or *Dys*-embodied

This section explores the participants' views on health and uses these comments to re-construct their taken-for granted embodiment. The data show how, for many of the research participants their body did disappear, or, when it *dys*-appeared it was not simply because of impairment, but because there were other contextual factors. The participants' subjective views of their own health was explored by asking them if they thought they were healthy. I was not really interested in their answers in terms of trying to uncover lay perspectives on health, as found in, for example the work of Blaxter (1990) or Herzlich (1973), but the topic was raised as a methodological tool through which an understanding of the participants' sense of embodiment could emerge. In general, however, the majority reported that they viewed themselves as healthy, or pretty healthy, with only a few, all women, defining their health as poor, or relatively poor. Some of the informants made specific mention of their impairment, or

² This may in part be due to the fact that it was my main area of research and also an area in which I was aware of much of the research literature.

³ Whilst this work was not published until after the data collection for this study had been carried out, I first became aware of this work in an internal seminar at the University of Edinburgh in 1994 and it was very influential as I formulated this research.

impairment related conditions. What Blaxter terms functionalist explanations of health are a theme which recur in many of the accounts. As Sheila puts it:

NW: How would you sum up your own health at present?

Sheila: Good.

NW: Good? Why?

Sheila: I've got no problems. I'm never at the doctor and never stuck in bed.

I'm always flitting about, I'm never in, I would say.

Despite any direct reference to the body, this is very much an embodied account, in that by having what she describes as 'no problems' she is able to do what she wants to do. It is this issue of 'no problems' that is important here. Her impairment is not seen as a problem, it is not currently affecting her life and is, therefore, irrelevant. Whilst her impairment is, obviously, always present, it is not always attended to. It is part of her, but has little impact on what she wants to do. Her body is, as Leder (1990) would see it, absent. For her, having an impairment is not salient, it is not appearing as a 'trouble', it is just part of her. Jane goes much further than this, in that, whilst acknowledging that she has an impairment, she claims that it is of no importance and places no restrictions on what she wants to do, or can do:

*Jane: Well I feel good but I don't look on myself as disabled. It's my legs
that don't work, the rest is fine.*

NW: So you view yourself as healthy?

*Jane: Aye. Because I can do everything an able-bodied person can do. You either
sink or swim - you've got to accept or go down.*

The constitution of the body as an object, how it is perceived, is, as Merleau-Ponty (1962) would suggest, dependent on intentionality. This is clearly expressed in the comments above and of Tommy, who after describing himself as healthy when I asked him to explain what he meant, replied:

Tommy: It's being able to do what you want. From the wheelchair point of view.

NW: What do you mean?

*Tommy: Well there's certain things that you, it's being able to do everything that I
can, that I want to do, in a wheelchair.*

and Stella, in the first interview said:

I think because I am clearly operating at a, for me, 150% level of activity and not feeling completely knocked for six as a result. So I'm feeling positively able to do that. I am not feeling over-tired and life for me is just progressing as I want it to.

In these two accounts, whilst there is clearly an acknowledgement of their impairment, the mention of 'for me' or 'wheelchair', and the idea of impairment as a constraining factor is present, it is not seen as something that punctuates their lives. That is, it is not separate to the flow of everyday life but is integrated within their lives and as such, it can be downplayed or ignored. It is 'unremarkable' because, as far as they are concerned, they can do everything that they have become accustomed to being able to do to. The body is adequate for what they intend to use it for and is perceived in such terms.

In this sense, one could also argue that these participants have reformulated their habitus. Through phenomenology, their disposition, their way of being, their habitual state is one in which having an impairment is normal. As Bob argues:

My disability was fairly early on - I was only 13 days old when I caught this. So I've grown up with all the knocks and the snide remarks and so on. I just laugh them off, ignore them. I always have ignored them because the disability is part of me, it's my disability and it'll never go away so it's up to me to make sure that my life fits and my disability isn't going to stop me from doing the things I want to. Or if anybody makes any remarks I have this awful bad habit when I get in a bit of trouble with my friends for it because they get embarrassed, if anybody says anything to me about how I walk or something like that, I always have an answer for them.

This resistance to general views is discussed in later chapters. What is important to this section is the fact that the body is not being denied. Indeed it is being acknowledged in the fullest sense, but it is on his own terms, within his own set of values. It does not appear to be a conscious decision, it is not an attempt to, what some may describe as, deny the presence of an impairment, nor should it be seen as an attempt to downplay the importance of impairment. It is just that he has one but it does not interfere with what it is that he wants to do.

Agnes's account is particularly interesting in this context. Just before the first interview she had had a diagnosis of heart disease and had spent a short period in hospital, her foot was troubling her and she was unable to get out of bed. As she makes clear, it is these that impact

on her embodied being rather than what would be seen by many as her 'primary' impairment, rheumatoid arthritis.

NW: How are you at the moment?

Agnes: Fair to middling, fair to middling, in that I have a very bad foot at the moment which means I have to stay in bed. I have been very ill because I had a bit of heart failure which caused coronary oedema and very serious breathing problems and that is something that needs to be kept in check all the time now. But apart from all that, I keep well.Considering things before the heart problem that was diagnosed last year - I was really very healthy in general health, I kept very well for many, many years. I live well I don't do anything that is detrimental to my health.

She clearly brackets arthritis from her subjective analysis of her health, in that there was no mention of it in her account of her current health status. Later she argued that, provided people 'do things that keep them healthy', arthritis should not be a problem.

Disability and general health are two different things really. You can be disabled and it can affect your general condition which the heart condition did; that made me feel very ill and very unwell which produced other problems. The arthritis is a separate disease; it shouldn't, all things being equal, you shouldn't be ill unless of all these other factors - you're over-drinking, you're over-eating. If you have arthritis and you over-eat and become fat and obese, then you are not going to be able to walk or move properly so therefore you ought to do the things that keep you healthy because you have a disability. But I think I would do that whether I was disabled or not. I think that is the kind of person I would be - I would want to keep healthy

She went on to state:

I didn't worry when I had the arthritis; the heart, which is your main organ and rules everything. If you haven't got a good heart then it affects so many other aspects of your health and so I now have the additional problem of that and it means that you have to fight harder to keep healthy, in general good health. Whereas before, general health was easy to do because I lived well.

Agnes does not see arthritis as a source of illhealth. It is a condition of her existence, something that she has had to live with nearly all her life, but also something that has become incorporated into her sense of embodiment. It was only the added complication of heart disease that has caused her to feel unwell, that made her body *dys-appear*. Arthritis is not something that she can control, but she has the ability and resources to tackle it, it is part of her being, her habitus. Heart disease was something new, something that was outside of her experience and the enforced hospitalisation that she faced following its onset challenged her sense of equilibrium, upsetting the status quo. She was no longer able to do what she had previously done, and her perception of her body, and her bodily practice is altered.

Normal is as normal is, and for these people it is normal is to have an impairment. When Grosz writes, in her account of why people experience phantom limb sensations:

The phantom is an expression of nostalgia for the unity and wholeness of the body, its completion. It is a memorial to the missing limb, a psychical delegate that stands in its place (1994; 73).

it is clear, that, she is unable to imagine a body that cannot be complete. That for her, a phenomenology of the body can only be based on normative assumptions of the body. This is particularly ironic given that one of her major critiques of Merleau-Ponty is his normative stance on sexuality. For many of the informants impairment had become normal, it is just part of their embodied experience.

For others, however, impairment did play a part in their description of their health and relationships to their body. Archie, for example defined his current health as 'pretty good' because he was free from specific impairment related conditions which prevented him from being 'fit' and able to do what he wanted:

I think my health is pretty good at the moment. It's been, the last year, healthwise, I've been pretty clear, like, with infections and, urine infections and any other illnesses. I've not had any illnesses in the last year, so I've been pretty fit, but the year before that I was suffering quite regularly with urine infections, this was over the span of a year. But I managed to get cleared up, and I've not had a urine infection for about a year now, so my health is, I'm pretty stable apart from the odd cold or something like that.

Here, it is not the impairment per se that is the issue, but complications that can arise from the impairment (in this case paralysis, resulting in the need to use a catheter and the consequent risk of urinary tract infections, UTIs). It is these, and not the impairment itself that makes the body *dys-appear*. When these are brought under control, and he is able to do all he feels he wants to do the body can again disappear.

UTI's were raised by a number of the participants as an issue of concern and for some they clearly affected their embodied sense of being, the taken-for-grantedness of the body. Arnie was one for whom UTIs were a major concern. He described how he constantly monitored his fluid intake and often felt responsible if he got one:

If I get a UTI, I tend to feel very annoyed with myself that I've let it happen in the first place. Sometimes these things are unpreventable, but a lot of the time they are preventable by drinking enough fluids.

However, for Tommy, UTIs were just a fact of life, something that he had got used to and he just got on with it. He told me how he felt 'easy-oasy' about getting them, 'you just take your medicine, go to bed and in a day or so everything's ok'.

Joyce was one of the informants who described her health as poor, and in doing so her body *dys-appeared*. However, she did so by contrasting her current health status with that of her own past, not in terms of her impairment. This is important, as it suggests that rather than adopting a normative understanding of her body and health, she has used her own embodied experience as the yardstick against which to judge herself. That is, her habitus, her embodied sense of being, is one that includes impairment. Joyce does not have a so called progressive condition, neither is it acquired:

Well, I have actually had a water problem for the last three years and I am not as healthy now as what I should perhaps be, because three years ago I was on my feet every day walking with sticks constantly. Then I just had water trouble and in the last three years, just after I was married. They thought my water trouble actually started because of certain pressures that were unexplainable and my body just changed. I started sort of being incontinent for a while, so I have been attending the clinic at the Western for the past three clinics and they just put me on tablets about a fortnight ago or eight weeks ago and I had bad side-effects to them so they have had to take me off them again. I go back to the Western General to see the specialist on 7 February, to start back at the drawing-board. But when I go to the

hospital on 7 February, I want to have a general chat about what my walking used to be and how my walking is sort of non-existent anyway. Because I feel it's important that I get back on my feet again.

Here she talks about her 'body changing' and it is this change that has made her body *dys-*appear. Her wish to get back to walking is not, as she makes clear, related to normative values of the importance of walking around, but:

Well, walking - even though you are walking with aids, your metabolism is moving more so you are not just sitting stationary and putting on more weight. I mean, since I have been in the chair for the last three years for instance, I have had to cut back my intake of food simply because I would put on more weight sitting down. It's just that, my feet have been swelling up and I have had other symptoms related since I have been off my feet, like things I've noticed.

Walking was not a defining characteristic, but if she had been able to walk she felt that she would have been able to achieve a higher level of physical fitness, and it was more the fact that she was unfit that made her feel that her health was poor than the fact that she could not walk.

Well, like, say, in the past I was also doing my sports activities before my water problem started - like track and field events. And even though I never did it in the Olympics or actually competed in it, it gave me - because I was doing sort of weights and track and field and that, it kept me occupied. I was meeting people at the same time. So a lot of the problems I've now got because I'm not so active with my sport and that, things have sort, my legs swelling and that ...

Importantly though this is not a reference back to a time when she was not impaired (her impairment is congenital), but to a time when she felt fitter, more in control, before her 'body had changed'. This lack of physical fitness, was also the reason given by Collette, whose mobility impairment had been exacerbated not because of any disease progression, but because she no longer had time to devote to exercise. In Joyce's account of why this was important to her she again clearly lays out a personal, functionalist perspective of what it is that she wants to be able to do. For her it's not about a normative standard, but one that is based on her own experience of her body:

Joyce: [Being healthy is] not necessarily doing exercise and being fit, but just feeling healthy; being able to walk up and down some stairs without pecking too much.

NW: What do you mean by that?

Joyce: Well having a sort of level that you feel comfortable with. You know, you know that if you do too much you are going to feel uncomfortable, but you've got your limits. You know you are not going to do anymore than that, but within that limit you feel fine.

Many of the informants talked about their health in terms of being able to, as Deirdre puts it, ‘... well, get out and about and stuff like that, and being able to meet with people, you know, just enjoying life to the full really.’ There is a real sense of embodied being in many of these accounts, but it is not the impaired body, but a functional body, one that is able to do what it is that the participants expect it to do. It was linked to being able to fulfil social roles. Joyce, in the comments above clearly states how her ‘water problems’ are affecting her ability to socialise. For some it also took on a political basis, in that by being able to function at the desired level the informants were able to compete on an equal footing with non-disabled people; as Stewart says when defining what being healthy means to him:

Allowing me to attend meetings, allowing me to do all the normal things others do - go out to pubs, go out to dinner, the cinema, family and friends and generally socialise and still conduct myself at meetings. By going out to meetings and participating I feel that I am competing on an equal basis.

This relates to what Saltonstalls (1993; 9), refers to as ‘the self-soma process’, in that by being healthy and able to fulfil desired roles, the body and self are not divided. It is through the possession of a functional body that the informants were able to meet the everyday demands that they faced and to resist the subjectification which they, as disabled people, faced on a daily basis.

These accounts show how impairment can become part of the embodied experience, the presence of an impairment does not, necessarily make their body *dys*-appear. Further, for some, whilst the body is apparent in their description, it is not because impairment *per se* is perceived as the ‘trouble’, but the body *dys*-appears because of change.

The Dys-appearance of the Body

This section explores further how the body can *dys*-appear. It first explores the accounts of those for whom the body seems to be always present as a result of their impairment and then moves on to explore how the body can *dys*-appear in many everyday settings and explores issues to do with gender, fatigue and environmental barriers.

Dys-appearance and Impairment

For a small number of the informants, however, the body *dys*-appeared and did so as a direct result of their impairment. Caroline, for example, told me

I cannot accept what's wrong with me. I keep.. I keep having this imagination in my head and think, one day I'll be able to get up and start walking, and you know, I just can't accept it.....I just have to get so much done for me, and I can't do ordinary things like changing beds. There's certain things I'd like that I can't do now, like when I go to bed, I can't manage to get myself from the chair into the bed, I have to get a help over. Well, actually, I've got a hydraulic hoist, you know? I think I'm a burden, I really do.

Impairment, according to these accounts, interferes with their day to day activities. For example, Eve told me how she is unable to do things that she feels that she wants to do. She has recently had to stop driving, had given up work and was having problems reading. Her impairment had caused her body to *dys*-appear. She was forced to focus on her body, her embodied being was constantly changing and this caused her to constantly have to renegotiate her relationship with her environment. What she saw as her inability to fulfil social roles and to carry out desired tasks had caused her to re-examine her relationship with her body. Her body is constantly being brought to her attention and cannot be taken for granted. The difference between this view and the views of, for example, Joyce and Collette, is that it is not seen as a passing phase, as something that can be altered through taking more exercise or through medical intervention, but is seen as a consequence of the impairment itself and the embodied experience is read through the impairment. It punctuates her existence and cannot be bracketed out.

For Eve having an impairment challenges her sense of embodiment, it is more than what Bury (1982) terms a 'biographical disruption', it is her biography. The presence and nature of her impairment prevents the establishment of an equilibrium and does not allow what Williams (1984) terms 'narrative reconstruction'. She is unable to legitimate or explain her condition.

Caroline and Lucy, who also both have progressive conditions, took a similar line to Eve. They both felt that their impairment prevented them from doing the things that they wanted to do. For example, Caroline states:

To me, to be healthy is to be walking, um, in my mind, I know it's a terrible thing to say, but people in wheelchairs should be allowed voluntary euthanasia. Because I certainly would. I think the quality of life has gone when you're in a wheelchair. I think, you know, personally.

However, for others, the progressive nature of their condition had become part of their embodied being. As Stewart puts it:

For years, I guess I have always said 'Look, I look much fitter. If things would stay at that level I could cope'. And then they move on, and you just move with it and you have to adapt again. But again you would say ... let's stabilise here ...

During the second interview when I asked Stewart about important things that had happened to him in the time between the two interviews, he talked about his holiday, getting his car back on the road and his relationship with his partner and made no mention of the fact that his breathing had deteriorated and he had had to start using a ventilator. For him, change and gradual disease progression was part of his life and was not worth commenting on. It did not represent 'trouble' in the way that, for example, Simon Williams (1996) seems to suggest in his paper on the vicissitudes of chronic illness, change over time has, for him, become normal. Whilst it may be true to say, as Bury (1982) contends, that having an impairment reduces one's ability to trust the body, it may equally be argued that some people become used to such an absence of trust and renegotiate what 'trust' actually means.

Dys-appearance and Gender Issues

It is important to point out that for many of the participants the body did at times *dys*-appear in everyday situations. For example, some of the female participants talked about their body in relation to concepts of femininity. Holly, for example, having told me at first how healthy she felt and how happy she was and that '*what's important is that I can... that I'm able to do a lot of things for myself*' told me how at times she felt 'ungainly' when she saw other, non-disabled people:

Em, I feel ungainly and definitely clumsy. But then, they don't think anything, I know. But sometimes I, sometimes I wish... see people getting up from a chair and

just maybe doing something, and I think... Oh, I mean....you don't, em, think... if I watch people walking along the road, or walking up and down the stairs, I think of myself not hanging onto the banister but - not needing a hand or anything. Or dancing. That's another thing I miss, yeah. But thankfully I'm not sporting minded, so I don't have to, you know, I never did. It'd be awful if... I think it would be awful if you were, if you did a lot of sport, you know, like my husband, and all of a sudden - well not all of a sudden, but over time - you couldn't do it, you know? I always say that, at least I don't have that.

Sandra told me about how at times, when her friends talked about their figure, their weight and so on it made her think about her body in a different way, something she tried not to do:

Sandra: I mean it's not that I blame my body for anything. It's just the fact that I am not particularly happy with it the way it is.

NW: That's not uncommon. 95% of other people might say that.

Sandra: I suppose that is quite true actually. I just - sometimes it annoys me, I think that is probably what it is more than anything. It annoys me that it doesn't work properly.

NW: Do you mean frustration because you can't do -

Sandra Yes. But I don't actually keep the frustration into myself because I know it is not going to make any difference. But just once in a while you get a flash, you know. I can't get into a building so I take it out on the building, but I might feel maybe that it annoys me that I can't get into the building as well because of me and the building. But mostly the building.

Dys-appearance and Fatigue

The body thus can disappear and *dys*-appear depending on the circumstances. People's embodied experiences are not static, they change over time and reflect the contingent and variable nature of their lives. Tiredness for example, overdoing things, can make the body *dys*-appear. As Moira says:

Well, with MS it's the muscles, I think my muscles get completely limp. So, you know, if I'm doing something I know I'll have to give it a rest because of... I'm going to overdo it.

Similarly, many talked about how because of their impairments it was harder to do everyday tasks. This is what Thomas (1999) would call impairment effects: yet, as many make clear, this is something that they have got used to:

I have learned to be patient because I can't get quicker. Sometimes it drives me completely bananas. I have learned, it is 12 years now since I had my accident and I have just learned to be patient because the alternative is just too stressful. I know once I have done anything once I know whether or not I am going to be able to do it and therefore with time it will get quicker but I will never be super-fast or I know I am never going to be able to do this and therefore this is something I need to buy in, I will get support to do, and those things one learns.

This account shows how, at times, the body can both *dys*-appear and at the same time disappear. He has learned how to manage the effects of his impairment. Impairment has become part of his habitus, that is it part of his unconscious being, but at times it can reappear. However, it is through phenomenal experience that he has altered his habitus. What Thomas (1999) refers to as impairment effects have become part of their embodied sense of being. These data suggest that impairment effects cannot be described as either biological or anatomical differences, but that an inclusion of the phenomenological experiences of living with an impairment must be taken into account.

Dys-appearance and the Environment

As many of the informants made clear, however, the *dys*-appearance of the body was often brought about through external factors. These external factors took a variety of forms, but the most common involved either interaction with other people or problems with access to buildings. However, in issues to do with access, there was almost always an interactive element, access was rarely described as an inanimate issue. As Archie says:

It is annoying if you go to discos and places like that where they've got steps and you go in, and you get turned back because you're in the chair, and at first it's just because it's a fire hazard, so I'll tend to argue - I mean, I have argued with the bouncers and the people that own the place to say that that's not fair, just cos I'm

in the chair, that you don't want us in there, you say that it's a fire hazard. And we argue with them and tell them that we're just as much risk as anybody else, no different, and a couple of times it's worked, they've let us in the place and said it was fair enough, and then once you go in the place and they've realised that you're not a major problem and you're not an embarrassment to other people, and I think that's a major part of people not wanting you to go to....

Even when the issue is raised as a straight physical access issue, for example access to a particular shop, participants tended to talk about it in a relational, interactional manner. As Jane says:

Oh, I can get really angry at people's ignorances. I mean take [department store] for instance, that was refurbished. Now I went up on Boxing day with a friend, and there's no toilet facilities for disabled people. There were when it was refurbished. They had me on every floor to see if the staff toilets or the gents toilets or the ladies toilets would be suitable and it was, "If you care to write a letter, madam, we'll hand it on to the architects." Things like that really bug me....[I get] angry at them and their ignorance and angry that as disabled people that we accept it. I came home and wrote a letter, but how many other disabled people would?

The way that the informants talked about their relationships with non-disabled people forms the basis of the next chapter.

This section has shown how, for some, impairment fundamentally alters the notion of embodiment, that is their body is constantly brought to their attention. However, others' embodiment is often 'silent' and they are only made aware of it through other, externally produced factors. Impairment has become part of their sense of embodiment, part of their habitus.

Relating to the Body

Many of the participants spoke about their body, about the messages they received from it and the care that they took of it. It is this that forms the basis of this section. Leslie, a high level quadriplegic, describes how 'listening' to her body and being aware of what it is 'telling' her has become essential to her continuing well being. She described how, immediately following her accident, she felt like 'a head on a pillow' but she gradually became aware of the messages that her body was sending her:

I get a lot of different signals, like goose pimples if I've got a bladder problem or a bowel problem, I spasm if there's something going on. Goose pimples, they're a great indication that there's something wrong with my bladder. Unfortunately I get it just as it's started to leak. If I had them just before, the problem could be dealt with - it might just be the position that my catheter's got into, so it's still good in that it has prevented a lot of disasters. I've gone goose pimples in bed, suddenly realised, had a wee feel down, got it all sorted out, whereas had I not had the goose pimples I could have lain on for another 4 hours and been saturated without knowing it. So I get headaches if there's things going on. I know when I've got a really big, blocked catheter problem because I take that very rare that I get that distroflexia condition and luckily I've got medication for that, I know what I've got to do.

This was a view expressed by many of the participants, especially those with paralysis. The data suggest that some people reformulate their sense of their body over time. Many of the informants talked about how much more aware of their body, in a medical sense, they felt they had to be. Having an impairment meant that they had to recognise whether the messages they were receiving were as a consequence of their impairment or some other, unrelated condition. For example Joyce told me how she had once had fainting fits, and felt sick as a result of a 'grumbling appendix' and she herself had to recognise the difference between these feelings and those associated with her impairment, as she says:

For instance, a lot of disabled people, because they have a lot of difficulties to overcome, sometimes you can't tell when it's not your disability.

For this reason some of the informants talked about how they needed to be more in touch, more aware of their body than non-disabled people, as Agnes says:

NW: You think you have to be in tune with your body when you are disabled?

Agnes: I would think so, yes, more than the average person. Things make themselves more obvious when you are disabled. If it's cold out there, or something like that, that will affect you so it is the same type of thing; you are tuning up to 'Oh another cold day, I suppose I'll have such-and-such' or whatever it is. You actually become more aware of.....keeping warm or - yes.

Informants talked about how they needed to know and understand more about the workings of their body, the actual biology of their condition. Indeed they often felt that they knew more about their specific impairment than members of the medical profession, a point that some of their doctors conceded to them:

My doctor in ----, he said to me, he said, "Moir, you know more about MS than I do." He said, "You know far, far more."

Through this knowledge, either gained through reading literature about their particular condition, contact with others with a similar impairment or personal experience informants were able to challenge what they were instructed to do by their professionals; as Drew replied when I asked him about taking care of himself:

It's not the routine that I was told to follow when I was in hospital, you will also notice here I am sitting in my wheelchair a C5 tetra not on a RoHo or other type of cushion but a foam cushion and in the hour we've been in the room together I haven't lifted once. [My consultant] told me to lift every 10 minutes. There's not a chance that I'll do that. I've made a judgement that I don't need to and so far I've been right. There may of course come a time in my life when I have to, 'cos as I get older the wasting has reached the most, nadir if that's the word, and so I'd have to do those things.

However, for Tommy, becoming disabled had not affected his relationship with his body:

It's not been any reason to look at myself, it's purely, it was an accident and it happened, and that's it. I didn't think that it should make you come round, and why would you want more to look at yourself more now than what you did before. And I didn't see a reason why you should need to do that, so I didn't do it. Why should I want to scrutinise myself, look at myself more now than I did when I was able-bodied

This, for Tommy is a political issue, he is questioning the notion that because he is disabled he needs to be more aware of his body. He rarely checked his body for pressure sores, arguing that he knew what he had to do, and as long as he did it there was little chance of a sore developing. He did not want to see his life as one revolving around his impairment. This is not denial. He clearly took care to avoid complications. It is just that, for him, having a spinal

injury is not problematic. He is able to just get on with his life, has developed a new routine, one in which his impairment appears to be of little or no consequence.

In a similar vein, many of the informants talked about how they knew that there were a number of things that they should do, but rarely did. So for example Mark talked about how he knew that he should have done exercises to stretch his legs and that, because he had failed to do so, he could no longer fully extend them. This is a similar approach to life and the body that many non-disabled people take with regard to healthcare; many people knowing, for example that they should exercise, but failing to do so.

From these above accounts it should be clear that for some people with a physical impairment their embodied sense of being is one that incorporates, at times, their impairment. That is, having an impairment has become part of their existence.

Further evidence to support this thesis is provided by the comments of many of the participants about other disabled people. In some of the interviews, the participants talked about other disabled people in hierarchical terms. Their own impairments were more tolerable, less debilitating than other people's. The most common of these was the claim that at least they were not mentally impaired. Some described friends or colleagues as people they would not like to be, so Leslie says:

People I've met with MS where it's started to affect their speech, and you can hardly make out what they're saying and you get irritated,... I've met people with MS, and it's dreadful because people really do think you're stupid and they just kind of laugh you off, you've actually said Oh my god, here comes Sam, because we can't be bothered making this big effort talking to this poor wee guy and it must be horrible.

Moira talked about how she often looked out of the window at 'poor souls in wheelchairs' and Holly said:

I feel grateful that it's not anything worse. I do really. I mean, it's bad enough, yeah, sometimes I think it'd be nice to just sort of walk, and like I was saying, run up and down stairs, walk along normally, em, go and dance, whatever, yeah. But you know, still, I think, you know, others are a lot worse off, I've certainly seen that round here too. Yeah, you know

What is interesting here is that both Moira and Holly would see Leslie as a 'poor soul' or a 'lot worse off' whilst Leslie would describe them as having a terrible condition, that is MS. Similarly, Jane talked about how she did not know if she could have coped with being non-disabled and acquiring a disability in later life;

They regret what they have had. I can't regret what I've never had. I noticed it more so as years get on I notice it more because there seem to be a lot more people struck down with illness now and accidents and most of my group it was polio or TB or things like that, you just accept that you were one of the unlucky ones, you contracted it. When I was on holiday it was, all you were meeting was disabled people. Some of them you could have just cheerfully shaken. Get on with your life, it is for living. And others you just feel sorry for.

What do you mean feel sorry for.

There was one girl there she had been struck down with a fork lift truck cut both her legs off. In a matter of minutes that has changed her life. She was quite bitter. What can you say. Life's for living, but she didn't see it that way. Give them a bottle of pills and a bottle of water. If it is that bad. But everybody is different.

This is not identity formation as Douglas (1966, 1970) or Crawford (1994) and others use the term, in that the informants all recognise that they themselves are impaired⁴. They are not attempting to create a category of people that excludes themselves, and neither are they acting to bolster their own self-esteem. It is not definition nor is it self-validation. It is that they live with their own impairments and have become used to their own condition. However, when they look at others they feel unable to comprehend how others manage their own lives. Their sense of embodiment is thus a product of multiple forms of interaction, existing both within social and cultural norms yet, on a personal level, challenging these norms.

The Responsive Body

I wanted to explore how the informants felt that their body, and their relationship to their body, was affected by their mood, their emotions and their feelings. This idea was one that emerged from the first interview. I was driven in part by comments from some of the informants when they talked about their feelings about themselves, for example Deirdre described to me how:

When I'm down self esteem goes out the window, I feel dreadful about myself.

And Sandra said:

Sandra: If I'm depressed I feel worse about myself.

NW: In what way?

Sandra: I just get paranoid, you know, everybody is staring at me all of a sudden and everybody is looking at me and thinking 'Oh, she is stupid as well'.

Also I was interested in trying to learn why some of the informants talked about themselves and their embodied experience in the way that they did. It is possible, from some of the comments to suggest that feeling down⁵ might have altered their embodied being.

I asked if how they felt had any physical effects on them in an attempt to explore the notion that not only does the body send messages to itself regarding change, illness or pain, but also that the body can act as a conduit of feelings and emotions. Some of the informants talked about how their impairment was modified depending on the mood they were in. For example Bruce described how his speech got more slurred depending on both his mood and physical state. As he became tired or stressed he was unable to control his talking, his spasticity increased and his mobility worsened. This was evident in the interview as his speech notably improved as the first interview progressed. James talked about how he felt "more able" depending on his mood. This is very similar to the ideas of Scheper Hughes and Lock (1987).

For these informants it is almost as if the impairment acts as a fault line, emotions erupting and exposing themselves through the physical weakness. The impairment is intensified, which can lead to even more frustration; as Sheila says:

The more frustrated you get about something, you work yourself up. At the end of the day the balance is off because you're tired and you've been on your feet longer. It works that way. I can feel that my walking isn't as good as when I started off and it bugs me and it annoys me, and there's times when my disability really gets to me.

⁴ The issue of identity is discussed fully in chapter six and seven.

⁵ The notion of "feeling down" is used in preference to the concept of depression because of the medical implications of the latter term.

However, others, such as Keiron, whilst they felt that their impairment was exacerbated by their mood, challenged this notion:

I don't come home and say things like, I'm feeling pissed off so I'll sit and think of about 20 self-slagger gags in 5 minutes, all my life has been so terrible sort of thing. I don't go home and bang my head off the wall and all that sort of stuff, I get irritated but I find ways of dealing with that.

Others described how they felt sure that there must be a connection feelings of mental wellbeing and their body, but were unable to give an example, so Stella says:

NW: Do changes in how you feel have any physical effects on you?

Stella: That I am not sure about. I know they should do, but I am not sure.

NW: What do you mean?

Stella: I do believe that if you feel physically well and if you feel happy or contented, then physically your body should actually be functioning much better. I can't say I've great amounts of evidence to show that.

She did however add that when 'things get on top of me' she had a tendency to get 'more frustrated with my impairment, my physical inabilities.'

Feeling down or "out of sorts" served to make the impairment more visible to some of the informants, not only did it make it more visible to themselves, they also felt that it was more visible to others, even though they knew it wasn't. As Deirdre says:

Deirdre:if I'm really low and down and I can't see any way out of it, then that's the time where, where I'm usually so positive, it doesn't stay like that, you know. All my positive feelings are pushed to one side and I think, I'm this and oh I'm that. . .

NW: Do you get pain or spasm or anything like that?

Deirdre: I get, like panic attacks, an awful lot. I just feel like, although people do like me and stuff like that, and when I'm all right about thing, I know what they're doing, I know it's right. But when I'm low I can't see like that. I think people, all

these folk, they're, "Oh she's at it again," but they're not, but I feel like, I'm doing this again, and folk are thinking I'm making it up and things like that.

Leslie took a similar line to Deirdre but described how, when she feels down she starts to feel lethargic and then became resentful towards other people:

I start thinking things like, "It's not fucking fair, there she is, doing all this and running about and..." you know, "I can't stand all these young folk are around and all these people are walking about with their families and my mum and dad, and I'm parked outside a shop like a dog" so I have a good old moan or I will get resentful perhaps towards the actual friend and I get jealous if a group of friends are going on holiday or a couple of couples. My sister and her husband for example, they go away with another 2 couples.

Not only does Leslie become focused on her impairment, but also on social exclusion, and on disabling barriers. However this focus is individualised, not as a political challenge to the way that society is organised. The tone was very different to the one that she employed when she talked about how difficult it was to find an accessible cinema or restaurant in her locality. It may be argued that it is through emotions that Leslie and others become aware of their body, of the way that society is organised to exclude them and the pervasive cultural ideology that is evident with regard to impairment.

For Archie, whilst acknowledging that his physicality can be affected by mood, described how he himself was often unaware of this:

Well, me, if I feel down, it does tend to make my body feel worse, because I tend to get the shivers and things like that, you know, and my wife can see, if I'm ill, she'll be like, 'You look really down, and you're ill.' She can tell by my physical well being, and you know, my face, and just how lethargic I am, that the more depressed you are the worse it gets. She has said that, I mean, she has noticed that. But me personally, I haven't noticed that, but she notices... she'll say to me, you look awful run down today, you know, things like that.

So whilst the body can be a signifier of both mood and health status, for some this may be missed. They are not always aware of what their body is telling itself and, in a similar manner in regard to stress, be unable to take any action that may ameliorate the situation.

The relationship between the body and mood also incorporated a notion of care of the body, the less at ease that one feels with oneself, the less care one takes of oneself. As Marion argues:

It slows you down and you can't be bothered doing anything so therefore you're inclined to sort of, oh what's the use of worrying if I put on another 2 stone or whether I put on 2 inches, just comfort eating for the sake of comfort because you are depressed, you sort of let yourself go.

There were also a number of informants who felt that they had never been depressed so were unable to answer this question. Tommy commented on how, when he first broke his back, the medical staff in the spinal injuries unit felt that he was in "denial", as he says:

Because they come up to you, and they expect you to be depressed, you know what I mean, they expect you to be depressed because it's a traumatic thing that's happened to, it's going to completely change your life. So fucking what?! Because it's happened to you, are you still not going to be able to do what you want to do, are you still not going to be able to go where you want to go, you know what I mean. Of course you are, because if it's somewhere you can't get into, take somebody who can help you in, tell them you're coming, they'll help you in. If it's somewhere you want to go and you cannae take your car, phone somebody up that can help you get there. There's always a way round it, really. Don't take the defeatist attitude, like, I can't go there because they've told me I canna get in, or they're not prepared to let me in. If they're not prepared to let you in, because it's going to be a hazard, fair enough, if they're still going to let you in, take somebody that can help you get in.

For Tommy, to admit to depression appears to be an admission of failure, an acceptance that he is unable to do things. As he sees it there is always a solution to a problem. It is as if by failing to be depressed he has failed to come to accept that he is disabled and that he must be made to grieve. Drew described how he was referred to a psychiatrist because of his responses to his injury:

I do recall, a shrink came to see me when I was in hospital. I didn't ask for him. The Shrink came because the nursing sister believed that I was unnaturally quiet and reserved, not engaging with people in a normal way and this began to worry her and she must have conducted her own tests, I wouldn't have known, and she

decided that I was withdrawing from the world and was not coming to terms with my disability and so a few weeks later, by this time I had come off the Striker frame and was in a standard hospital bed, this guy came and now I think the guy must have been a caricature, he had a tank top on, all the rest of it, a knitted tie, the whole business and he just appeared, and he sat on the bed and talked to me for a while and said eventually who he was and he was saying how are you and all this and I said I am fine. And he refused to accept that. I couldn't, I wasn't allowed to exhibit perfectly sanguine opinions of myself, my situation and the world. The presumption that there was a set of, a range of emotions that disabled people must have. I also had a discussion with an occupational therapist about the stages through which disabled people must go and said, no matter how short these stages are, they could be weeks, months of years, everybody have got to go through all the stages. Grieving and all that sort of stuff. I said I don't recognise having gone through. And her response was you must have gone through them even though you don't remember.

It is this idea that disabled people must be depressed that many of the informants felt was prevalent within society. If they were depressed or down then it must be because they were disabled. For example Keiron talked about how the death of his father had upset him, but that many people at work felt that he was down because of his impairment, or that, in some way this accentuated his depression. It was almost as if disabled people are not able to express the full range of emotions, as Stella says:

I think they probably have very stereotypes, very limited expectations of how I should be but they probably do have them like I probably don't feel things as strongly as other people.

Three of the informants felt that their life was almost permanently miserable, that they were never happy and they argued that they never felt at ease with themselves. They were therefore unable to reflect on the notion that their moods affected their health. Their life was on an even course, one of doom and gloom and that they experienced little change in that respect. As Caroline put it when I asked why she had, in her own words "opted out of life":

Caroline: Nothing ever changes.

NW: Is there anything that gives quality to your life at the moment?

Caroline: Nothing.

This emotion as well as being expressed through a dissatisfaction with life in general, orientates the individual towards their impairment. The impairment becomes not just the root cause of the individuals' problem, but also the way that their emotions are expressed. As Eve says:

Eve: I feel I've given up

NW: You feel as if you've given up?

Eve: Yes. (at this point she broke down in tears)

NW: Is it all right to carry on with this?

Eve: Yes... the consequences of so much I can't do have ... I have just given up on everything.

She talked about how isolated she felt where she lived, that her friends no longer visited her and that she was unable to lift herself out of the depression. She also talked about how her MS had necessitated her giving up work:

Because the MS was so active and I can't write now and I needed to write a lot for work. I needed to read a lot - I can't read now. It just got so impractical.

This has further added to her isolation. The connections that she herself made between physical and mental health can thus work as a positive feedback loop, spiralling down, impairment accentuating the feelings of depression, which in itself accentuates the impairment and so on.

I asked these three informants if they would be surprised if I told them that many of the other participants in the study had described themselves in very different terms to those they used. Caroline replied:

Probably not. I'm thinking, last week on a programme that I saw, This Is Your Life, and I can't remember the boy's name who was in a wheelchair, he was born with spina bifida. And he seemed to have a great load of things that he did with his life, you know, and he seemed to be really quite happy with the circumstances. And yeah, I'm sure there's a lot of people happy with that. I think I'm probably more unhappy now because of my daughter's circumstances.

She also talked about her problems with her relationship with her husband and the absence of friends. Similar points were made by Eve, and Lucy. It could be argued from these accounts that it was not the presence of an impairment but social and material conditions through which ideas around their embodied experience were constructed. As Schepper Hughes and Locke (1987) have argued, emotions can provide a link between the body and the mind. Whilst for many this is seen as emotions that derive from having an impairment (see for example Bendelow and Williams 1995), it could equally be argued that emotions that arise from external sources can also link the body and mind in disabled people.

It would, however, be too simplistic to suggest that these informants have been unable to incorporate their impairment into their embodied experience and for it to become part of their habitus purely because of dissatisfaction with their life and their material existence. Yet, for whatever reason, these informants have a very different sense of embodied consciousness to the other informants. It may be argued that in any group of individuals there is bound to be a number who feel 'down', and, given the high degree of discrimination and exclusion experienced by disabled people, it would be surprising to find a group of disabled people which did not include such people.

Conclusion

This chapter has presented data which explore the embodied, taken for granted perceptions and practices of having an impairment. It has shown how, for some of the informants, having an impairment does not, of itself, make the body *dys*-appear. The data challenge the prevailing orthodoxy within much of the writings in the sociology of the body which suggest that disabled people are always already aware of their body. It becomes central to their experience, but not as part of them, but as an alien, *dys*-functioning object. For many of these informants however, whilst their bodies were obviously present in everything they did, this presence was, phenomenologically, unremarkable. The body did not, of itself, create a resistance and so demand attention. It is present, but only in a state of continual disappearance. The body, despite the impairment, is taken for granted and in much the same way that health only becomes a salient issue in its absence, so the body only became salient in certain circumstances, when it meets resistance. These resistances can take on a number of forms: for example, the muscle strain and exhaustion experienced as a result of over-exertion which may or may not be related to the presence of an impairment; social dissatisfaction with the body, an experience described by some of the women, or the presence of environmental barriers.

At other times, when the body was present, this presence seems to be no different for many of the informants from that of other accounts of health and illness, or of the body in everyday life (see for example Cunningham-Burley and Milburn 1998, Saltonstall 1993). In everyday life the

body, for these people, was an absent presence. Impairment has become part of their existence, their habitus. It could be argued that if they were to suddenly find themselves free from their impairment, it would be this that would spell 'trouble' and they would have to learn, or relearn, how to live their lives without an impairment. This is precisely what happened in the account given by Oliver Sacks (1985) of a blind man who recovered his sight, yet still spent most of his time living in darkness, shaved with the lights off and so on. Being blind was part of his phenomenal being. So, for some the informants in this study, is having an impairment. Whilst, from a normative perspective, it might be hard to believe that impairment can become a taken for granted or routinized; for those who live with such conditions it appears that, for some, this can happen. The impairment becomes embedded within their sense of being, it becomes phenomenologically absent from view. As Schutz (1970;27) points out, through experience we learn what parts of our lives need specific attention and what parts do not. For people with impairment, for the majority of time, they do not need to direct any more attention to their body than those without impairment. There are however, specific times that they need to be aware of it, for example in the prevention of UTI's or pressure sores or when monitoring their bodies for signs of illness.

Relevance of the body should be discussed, therefore, from the perspective of the people whose bodies are being discussed, not from that of a non-disabled person. The accounts call into question the simplistic notion of a binary built on the idea impaired/non-impaired. By what criteria is impairment to be judged; is it to be on a pathological or anatomical basis or on a phenomenological or experiential basis? That is, if people ignore their impairment when giving an account of their embodied being, should this be seen as a true account or should social scientists base their analysis on a biomedical understanding of what a 'normal' body is. This analysis of the data presented here would suggest that for some disabled people, impairment can be, and is, an absent presence in much the same way as the body is for non-disabled people.

Emotions and feelings appeared to be central to the informants' accounts in which they talked about their relationship with their bodies. Feeling down, anxious, frustrated can all affect the relationship with the body and can serve to make the body alien. These feelings can be induced through tiredness, stress and interaction with others. The body *dys*-appears when it meets opposition, and, as Zola (1982) has argued, much of this opposition is socially created. However, some of the informants described how this opposition or trouble arose not as a consequence of society, but as a result of their impairment. Zola (1982) suggests that this ascription of trouble to the impairment is the result of societal attitudes. This thesis now turns to explore how these attitudes are played out in the lives of disabled people, how it is that they experience disablement.

Chapter 5

Daily Denials: The routinisation of oppression and resistance

Those we meet cannot fail to notice our disablement even if they turn away and avoid thinking about us afterwards. An impaired and deformed body is a 'difference' that hits everyone hard at first. Inevitably it produces an instinctive revulsion, has a disturbing effect. Our own first reaction to this is to want to hide ourselves in the crowd, to attempt to buy acceptance on any terms, to agree uncritically with what ever is the done thing. (Hunt 1998;12)

Introduction

In the preceding chapter on the body, many of the informants talked about how, for most of the time their body is of little or no consequence, but that they only become aware of it through either change, stress or when it is brought to their attention through other means. One of the most striking themes that emerged from the data was how often this was performed in their interactions with non-disabled people in that they were reminded of how they were different, or seen as different. This difference was made apparent through language, through behaviour, through a look or a sideways glance. Discrimination in the manner documented by, for example, Barnes (1991) and Hyde (1996), was obviously present, but was experienced less through structures than through interaction.

This chapter therefore documents the informants accounts of their interaction with non-disabled people and the social and physical environment in which they live. It is restricted to accounts that the participants gave that were immediate, carried out in their physical presence and includes behaviour in public places, social encounters and private conversations. It is in these encounters that, as Goffman (1979) puts it "most of the world's work gets done" (p.x). Whilst, sociologically speaking, social institutions, relationships, social structures, organisations, social change, social movements and so on provide the subject matter for a sociology of disability, these emerge through the conduct of individuals. It is only through abstractions of such conduct that these structures are made manifest. These structures are experienced not as facts, but as an outcome. Social structures do not exist outside of the sociological imagination. So Lemert writes:

....social structures are by their very nature re-constructions of reality *after the fact*. No one ever encounters the reality of structures as such – not markets, not states, not stratification systems. Real people, rather, encounter insufficient pay checks, impossibly excluding bureaucratic rules, and particular slights and injuries, but not the

structures themselves. The reality of social structures is always, unavoidably, composed in the sociological imagination...(1997;74).

Structures are perceived as the product of discourse, they occur in language, and through social interaction. Social structures are contingent and invented, they do not rest on a solid foundation, but are open to change, to local reading, to reinvention. To discuss social structures without examining the language, the signs, the images through which structures emerge is to suggest that structures exist as some form of social reality, some tangible product that can be seen and felt. Elias's (1994) work on the changing nature of civilisation and the social construction of what is considered civilised, for example, clearly shows how these structures are continuously being destroyed and reinvented.

In the quote at the start of this chapter from Paul Hunt, he makes it clear that it is through interactions with others that he becomes aware of his bodily difference and that this awareness affects his behaviour. This is also a central theme of Jenny Morris' *Pride Against Prejudice* and some of the work of Lois Keith (1996). Both Morris and Keith argue that the prejudice experienced by disabled people in their day to day interactions with non-disabled people lies at the very heart of segregation and oppression and that it is necessary to understand disabled people's views and accounts of their daily round of social interaction. Through this an understanding of the patterns of cultural and social oppression of disabled people, of the challenges faced by disabled people and the structures that impact on their lives can be unpacked and interpreted.

The Importance of Interaction: Reclaiming social interaction

As stated earlier, social interaction is what makes the social world go round. It constitutes virtually the whole of human activity (Burns 1992). The work of Goffman has been particularly influential in this area, and a brief review of his work will be presented here¹. For a more comprehensive account of his work see Burns (1992). Goffman argues that social interaction constitutes not only behaviour in public places, social encounters, conversations, assaults and so on but also television and radio broadcasts and by talking to oneself (1981).

It is Goffman's work on the experience of spoiled identity that is of most interest to this study. In *Stigma* social interaction is premised on the notion that 'Society establishes the means of categorising persons and the complement of attributes felt to be ordinary and natural for

¹ For a more comprehensive account of his work see Burns (1992).

members of each of these categories' (Goffman 1968;11). A person's appearance allows us to place him or her into a category, allocating them what Goffman termed a 'social identity.' The categorisation system, for Goffman, exists outside of these encounters, and are applied unreflectively (p12). Similarly the concept of 'normality' is assumed. People with a visible physical impairment are, according to Goffman, discredited, unable to achieve full 'humanness.' So he writes: 'By definition, of course we believe that a person with a stigma is not quite human.' (p15) and people who are discredited face discrimination which reduces his or her life chances. This unequal treatment is, Goffman believes, justified by other, non-discredited people, through the creation of a 'stigma theory,' an ideology which permits such treatment of the discredited on the grounds of their stigma.

Through interactions, 'shared vocabularies of body idiom' (1963;35) emerge. These vocabularies allow us to grade individuals, providing us with hierarchies according to unspecified categories. Any violation of these situational norms are treated as signs of instability, body management being central to social interaction. Giddens (1991), drawing on Goffman and Garfinkel, applies similar criteria in his analysis of the body and identity. Not only can disabled people's bodies appear threatening, but by acting in unpredictable manners, for example spasticity, they operate outside of any 'shared vocabularies of body idiom.' An impaired body can disrupt the social hierarchy, disabled people are thus seen as dependent, what Goffman calls not quite human.

Further, as Lois Keith (1996) argues social interactions between disabled and non-disabled people are characterised by confusion and problem. She draws on the writings of Murphy, who argues:

The disabled person must make an extra effort to establish his status as an autonomous, worthy individual but the reaction of the other party may totally undercut these pretensions through some thoughtless act or omission. Even if the able bodied person is making a conscious attempt to pay deference to the disabled party, he must struggle against the underlying ambiguity of the encounter, the lack of clear cultural guidelines on how to behave and perhaps his own sense of revulsion (1987; 103)

She suggests that all rules become altered in the interaction between disabled and non-disabled people.

For people with a physical impairment, stigma are, in Goffman's formulation, embodied. The stigmata are also recognised by the stigmatised, who share the same sense of normality as the undefined normals (Goffman 1968;17-18). Impaired people are thus cast in the position of outsider, placed on the margins of society by virtue of their impairment. It is this embodiment

of stigma that is problematic in this analysis. Goffman is not interested in causes, he brackets any reference to the creation of these categories and while his work is more than mere description it is free from value judgements around how individuals interact with those he classifies as stigmatised. The concept of stigma, and its embodiment on the stigmatised ignores the broader roles of cultural representation which render disabled people 'other.' If the concept of stigma were to be recast around the concept of prejudice a far more powerful analysis could be achieved, in that the blame for such prejudice would fall squarely on the shoulders of the normal. It may be argued that he is only interested in spoiled interaction as a means to cast light on 'normal' interaction. Although, as Goffman himself argues (1963), we all have some stigma of our own, a point echoed in the recent writings of Bauman (1996).

Goffman has been widely criticised for his concentration on the micro and his omission of socio-economic power and inequality. His work has been criticised by many within disability studies; for example Finklestein (1981) accuses him of individualising the issue and Oliver (1990), of an over-reliance on psychological models and secondary sources. Oliver concludes:

...while stigma may be an appropriate metaphor for describing what happens to individual disabled people in social interactions, it is unable to explain why this stigmatisation occurs or to incorporate collective rather than personal responses to stigma (1990; 66).

However towards the end of *Stigma* Goffman clearly recognises that these criticisms could be made of his work when he argues:

Sociologically, the central issue concerning these groups [the stigmatised] is their place in the social structure; the contingencies these persons encounter in face-to-face interaction is only part of the problem, and something that cannot itself be fully understood without reference to the history, the political development and the current policies of the group (Goffman 1968;151).

Goffman's work provides, however, a crucial amendment to the social model theorists. By tackling the issue of presentational non-conformity and exploring the dominating effects that it can have on social interaction he challenges the assumption implicit in their approach, demonstrating that there is more to disablement than material, institutional or statutory barriers (Shakespeare 1994). It also clearly repositions the problem of impairment from the body to the social, in that it is the social that creates the stigma.

Prejudice

As a consequence of the prevailing focus of disability studies and its emphasis on the material we have a wide range of literature documenting the discrimination that disabled people face in the workplace, in health services and in education (see for example Barnes' *Disabled people in Britain and discrimination* 1991), but, with the exception of the collection edited by Hunt in 1966, there has been little exploration of the cultural representation of disabled people and the prejudice that this produces for disabled people. Oliver, as Shakespeare (1994) points out, barely mentions cultural issues in either of his two major works on disablement. Morris (1991) and Keith (1996) have addressed this issue, from an anecdotal rather than sociological perspective. Shakespeare (1994) has examined this from a theoretical angle. By drawing on the work of Mary Douglas, Victor Turner and Simone DeBeauvoir he argues that disabled people remind non-disabled people of their own mortality and morbidity and as such are scapegoated, becoming what Heavey (1991) has called "Dustbins for disavowal."

It can be argued that an exploration of the concept of prejudice implies an analysis that is rooted in psychology, suggesting a similarity to other phobias. It must be remembered that the prejudice faced by disabled people and the second class status to which many disabled people are ascribed, is the result of oppression. As Kitzinger (1987) argues, in relation to homophobia, there is a danger that a focus on prejudice can result in an analysis of 'personal pathology of specific individuals who deviate from the supposedly egalitarian norms of society, thus obscuring analysis of our oppression as a political problem rooted in social institutions and organisations' (p154). It runs the risk of individualising the problem (Plummer 1981).

However, as argued above, any quest to understand and challenge the oppression faced by disabled people can only benefit from an analysis of the ways in which prejudice is reproduced. This prejudice is produced in particular life-worlds and social contexts and such analysis allows for its contextualisation and examination of the apparatuses of society that serve to create the prejudice and constrain people's life chances. Through this a picture of how the cultural representation of disabled people is mobilised and reinforced and oppresses disabled people, from the perspective of disabled people, can emerge and it is also possible to see how in turn this might be curbed or dissipated. As Keith argues 'an analysis of these apparently minor, but actually very significant events in the lives of disabled people, what they mean and what effects they have on us, is part of the political progress disabled people are making' (1996; 75).

The Daily Experience of Oppression

All the participants described how, in their everyday lives they were the subject of oppression or oppressive practices. These however, tended to be discussed in interactional terms. Only rarely did they describe descrimination in structural terms, and then, as discussed in the last chapter, the issue was personalised. Indeed, many made excuses when, for example, they came across inaccessible buildings, blaming the age of the building or the city in which they live. As Holly puts it

I think some new buildings, I think they're very good. A lot of them are being built with that in view. But I do think, seeing old buildings, well, the building was there before, and you can't really expect... well, they do upgrade them a bit, but old department stores, like Jenners and things, there's an awful lot of stairs and everything, even to get to the lift. They can't really.... but I know that, so I wouldn't go there. I mean, I'm not one of those people who... I've heard them, disabled, they complain, they can't get into certain places, but they know that, so don't go there. I mean, there are places they can go, that are very good, and have ramps to go up, and what not. And so, there again, in saying certain, say if you wanted to go to a pub or a restaurant, something like, where I know where the loos are, I know I wouldn't go. Just go somewhere where the access is better.

Although violence was rare, three of the informants described how they had been attacked in the street. For example Sheila:

I was out with some friends from work the other week. I don't get as much slagging as I used to - it's younger people. But if I do I just give them an earful back. But I was walking down Lothian Road in the early hours of the morning there was a guy on the outside of the pavement and I was on the inside of the pavement, and I saw what he was going to do, he came from the outside of the pavement carrying his boxes of pizza straight in and kicked the crutch away. It's ignorance. He came from the outside of the pavement in, I could see him - smash, kick.

Arnie had also been the subject of a violent attack, but refused to talk about it, it was he said "too personal." Anne talked about how she often, especially late at night had to put up with comments about the way that she walks:

NW: Have people victimised you for being disabled?

Anne: Em, it can, right, it can happen in the street. Like a couple of Sundays ago... 'And what are you walking...' no, 'You cannae walk..' This guy was rolling down the window - I was at Haymarket end, going to see my friend, she wasn't in, right - and he rolled it down and said, 'Oh, you cannae walk right.' A complete stranger!

One of the participants had been the victim of sexual abuse, and whilst it cannot be argued that she was abused because she was disabled, her abuser was in a position of power over her, and able to use this power to allow him to both ensure her silence and her future co-operation. In this way he was able to regularly rape this woman, over a period of for three years.

These attacks are the consequence of both powerlessness and violence. As Connell (1987;107) argues, with respect to rape, violence should not be viewed as a means of deviation from the social order, but as a means of reinforcing it. Attacks such as these are very difficult, and at times impossible, for individuals to resist. Resistance at the time of the assault may antagonise the assailant and further the aggression (Carter et al 1988). Whilst the feminist movement has made violence against women visible, redefining it as acceptable (Kelly 1988), violence against disabled people has tended to be unreported (Shakespeare et al 1996). Disabled people who have been abused in such a way should not be seen as victims but as "actively engaged in a struggle to cope with the consequences of abuse" (Kelly 1988;159). The focus is then on the way that individuals cope with, resist and survive without damaging their subjectivity. In the example of Sheila above, when the abuse was verbal she felt able to respond, resisting the assault yet when the attack became physical she was unable to do so, resistance can only be achieved by dismissing the assault as the consequence of "ignorance". This is discussed later. Similarly with Arnie, the attack was something that he refused to discuss, a coping strategy that Kelly (1988) sees as an adaptive process to facilitate survival.

Other forms of oppression were also widespread. This took many forms, the most common of which was what they nearly all described as "Does she (or he) take sugar?" In this example the disabled person is ignored, and made invisible. As Arnie says:

It's more they look at you and they tend to patronise you, sort of pat you on the head, and if you're with somebody, ask, "Does Johnny take sugar in his tea or coffee?" instead of asking the person.

This occurred on an almost daily basis to most of the participants. Many of the participants described how they were often assumed to have a learning difficulty because they had a physical impairment, a relationship that they rejected and found offensive. Disabled people are

thus marginalised, excluded from the mainstream of social interaction, or have to overcome barriers to get there and to participate.

In other examples the disabled person is depersonalised, treated as if not only are they not there, but also as if they have no feelings, so Deirdre says:

The other day I was being pushed by a friend and somebody came up and said to him "Doing your good deed for the day are you?" I was too shocked to say anything.

Some of the participants also described how non-disabled people seemed to view them as incapable of doing things on their own, as being unable to manage their own lives. So Keiron says:

I mean myself and my dad we used to get this all the time, and I remember once being in Glasgow and there was a crowd of people that went to the garden festival there, and there was lady of about 60, and I was just sitting on the park bench and my dad was there and she said, "What home are you from?" because she thought the people we were with were all institutionalised, you see. And my dad said, "Nobody's from any home, we're just a group of people out for a day." And then she's saying, my dad was telling her some of the things that we did in the group and she looked almost amazed, it was this great big shock.

Oppression as Patronage and the Denial of Agency

Many of the participants described how they were treated as children. For example Leslie describing her relationship with her district nurse says:

She's got one of these cheery dispositions and she tries very hard to be on a level with me but it still comes through this kind of "You're a busy girl, aren't you, what are you doing today, oh you're working today, you're a busy girl" Or she brings a student in and she'll say, "This young lady, she's very busy, aren't you Leslie?" And I just think, "Fuck off!"

Resistance in this example is indirect, unspoken, but still present. In any relationship with health professionals, resistance is difficult, not only do they have medical dominance over the individual, but with disabled people the relationship is more intense, and at times more

controlling. Stewart talked about how he had to have medical tests to fly, something that he felt that he himself should be able to decide:

Stewart: I think it is unnecessary to do it because I know what I want in my own life and take the correct equipment with me that I require and I think it is again an infringement on my ability to travel.

NW: Right.

Stewart: I know what I can do.

NW: You don't think it should be up to the medical profession.

Stewart: I don't think so, I don't think we should have to turn to them and say look, is it OK to travel, I think I should be able to travel by myself.

By demanding such tests, his agency is removed, any notion that he may have knowledge of how to deal with his impairment is challenged. This serves to remind him that not only is he impaired, but also that major decisions about his life can be taken out of his control. This removal of control became particularly evident when dealing with professions allied to medicine, particularly the occupational therapist. Marion, when talking about her new bathroom and kitchen that was being installed at the time of my second visit, described how her views on any adaptations had been ignored by the occupational therapist. The therapist insisted on installing a new toilet of a different height to the previous one, a height that Marion found difficult to transfer to. Despite falling off the toilet a number of times the therapist refused to accept Marion's point of view and eventually she herself had to pay to have a new toilet fitted. In taking such action the therapist threatened to withhold payment for the rest of the work, saying that she felt that the new arrangements were unsafe. As she says:

I feel that you are hitting your head off a brick wall all the time and getting nowhere.

Nearly all the informants talked about occurrences such as these, illustrating the way that control is removed from the individual. Despite living with their impairments, and learning how best to adapt things around them their views are seldom listened to. They are powerless, and unless, like Marion, they have the financial capacity to rectify the problems created by others, they must live with the consequences.

Some informants also talked about how, whenever they had a medical problem members of the health professions rarely listened to them and tended to locate any health problem that they had in their pre-existing impairment. As Bob described a recent trip to the hospital and his GP following an accident:

My GP for example I walk in and he says "How is your leg", "Still here". "How is this, fine. Why are you here." "I just happened to crack my knee cap". He was looking at my bad leg so I said "Not that one, My good one." "How did you fall?" "Like anybody else." you know I mean to me they're silly questions but I suppose they're not. And I start firing silly answers back and I think now he realises that I tell him what is wrong with me. It's the same in hospital. You go in because, and I was on a trolley, the doctor came in and said "Knee caps", I said "No just one". "It says knee caps here". I said "I don't care what's on my sheet, it is knee cap one, left. That is the right one, that is the left one." It took him about five minutes for me to get him to realise he has to ask me the questions and I would answer him sensibly. He was going to ok, what was on the sheet. The sheet can only tell you so much, the patient can tell you a lot more.

So they don't really listen to you?

They treat you like a piece of meat. They know I am a wheel chair user. That is why you are in a wheel chair but if you have a cut finger, sore head, a patch over your left eye but they still see the wheel chair.

What this shows and what became evident throughout the interviews was how sophisticated the informants were in their use of, and relationship with, health professionals. When dealing with their GP or regular consultant many had managed to negotiate a relationship with their doctor in which they had taken charge and laid down the boundaries. As Stella says:

If I think something needs treating, I will discuss it with my GP and I'll ask her for a range of options. If I'm seeing a specialist, as I do occasionally, I will make sure that - well most of my consultants now know me enough to talk to me at a fairly sophisticated level - I just need to know all the information that's going. I haven't found that to be the case across the board. When you establish a relationship with a health professional, then you can work on that. There are several instances I can quote, however where my experience of health professionals are very negative.

In this way some of the informants were able to resist domination by the health professional, challenging the image of themselves as powerless, reclaiming agency. However, this was usually only achieved through prolonged contact

Many of the informants had taken part in “training” of health service professionals. Whilst they were unsure of the roles that the professionals expected them to take, they were very sure of their own reasons for taking part. John described how he went to the local medical school to tell the students how to treat him and people like him, to look beyond his impairment, to “tell it like it really is.” That if he was ill, they were not to look to his impairment first but to look at him as a whole. These are similar actions to those of the Boston Women’s Health Co-operative in America (Frank 1995). By challenging the way that they perceived professionals learnt about disability, they felt that they could alter the way that they, and others like them, would be treated in the future.

Oppression as the Product of Charity

The participants talked about how they were often patronised and treated as people who should be pitied, the object of charity. Javid described how, when he was sitting waiting for a taxi outside the theatre with his hat on his knees, a coach load of tourists pulled up and as they filed past him put money in his hat. Even when he told them he didn’t want their money they carried on giving it to him. He had to move back inside the theatre. This image of a disabled person as one in need of charity was, many of the informants felt, the product of the media. As Keiron argues:

When I was growing up, the only images you saw of disabled people were like a wee 5 minute piece on like Blue Peter or something where they'd say, "This year's special appeal, for a minibus," or whatever, this type of thing. Or you'd maybe see, I don't know, a play and I think a lot of the images, I can't stand things like Esther Rantzen programmes, you know, Hearts of Gold and all that, all this type of stuff because to that is very . . . Deserving cripples Yeah, it's all, "Does a lot charity," and it's incredibly irritating. I think how people are presented, it's like if they said, for example, if they said we'll portray black people so we'll only show bits of Gone With The Wind, everybody's a slave and that, everybody's stereotyped.

The media were felt to be at the root of many of the ideas about disability that were prevalent in society. Disabled people were portrayed, according to the informants as “less than average,” “as negative,” as dependent” and as “people to be pitied.” Many commented on the fact that disabled people were rarely seen outside of stereotypical settings; as Marion says:

Marion: Well they're not on the television enough, and if they are on the television, it's usually a very condescending story line that's used round about them.

NW: Such as what, what do you mean . . . ?

Marion: Well, they're the too poor person, you know, how can I put it, you feel that the people who are running the programmes have put them in just as a token representation, not for the main reason of why they should be in. Does that sound right? They're always given a negative image.

This was something that many felt was damaging to them, not directly as individuals watching the television, but as they negotiated their way through life. It affected the way that other, nondisabled, people communicated with them and saw them. Many talked about the rare examples in the media where they were presented in a better light and how this cheered them. The older participants talked fondly of Crossroads and Ironsides whilst the younger tended to focus on the few examples in more recent programmes. For example Anne:

Anne: Yeah, yeah, nobody would... but I have to praise, actually, Grange Hill for portraying a disabled person. I thought that was great. Have you watched Grange Hill?

NW: No, I've not.

Anne: There was a girl with CP, well, I'd say a lot worse than me. And I thought, good on you, because these workmen said, 'You've been a bit young to go to the pub!' And this lassie who was non-disabled em, she says, em, wait a minute till I get this right.... 'Haven't you met somebody with CP before?' And I was going, cheering at the telly. Cos the image they had got that...

When disabled people appear on television, they tend, in the main, to be in factual programmes which focus on their particular impairment. They are rarely seen in gameshows or in fictional programmes (Cumberbatch and Negrine 1992). Media coverage focuses on medical issues and cures (Scott-Parker 1989; Smith and Jordan 1991).

Becoming the centre of attention

Many of the informants talked about how they were often made the centre of unasked for attention, treated as if having an impairment makes it permissible for other people to ask them deeply personal questions, which are usually related to their impairment, such as "What is wrong with you, why are you in that chair?" and so on. This was not always seen as offensive, for example many of the participants felt that it was only natural that children should be inquisitive, "*Wondering what that big lady's doing in a wheelchair.*" as Caroline puts it. However, it was the reaction of the children's parents that many found upsetting, by pulling their children away, telling them not to stare and so on, implying that they were not to be looked at, that they were other, further making them invisible and increasing their marginalisation. Marks (1997) has likened this to what Hall (1990) cites as the question most frequently asked of migrants: "Why are you here?" and "When are you going back home?" (Hall 1990:44). She argues that by asking questions about an individuals impairment the very existence of disabled people are presented as a problem. However, it may also be argued that nondisabled people are asking such questions in an attempt to create a barrier between themselves and disabled people, to try and ensure that not only are they not seen as disabled, but also to reduce the possibility that they themselves are at risk of becoming disabled (See Crawford 1994).

For many of the participants, when they were asked what was wrong with them, or why they were in a chair it was seen as an opportunity to put their side of the story, to explain their situation and to challenge other people's perceptions of them: So Jane says:

You know, if you're out, say, and a child's looking at you and the mother'll drag them away, "Don't be rude, you don't look at them like that." But maybe the child just wants to say, "Why are you in that, what's wrong with you? Why can't you walk?"

And you're quite happy to answer those sorts of questions?

Yes. When my daughter first went to school she used to say don't take me to school, you dress like a tramp. And this really hurt me. But that wasn't the problem, it was the remarks being made to her because her mum was in a wheelchair. So I asked the teacher at school if I could go over and talk to the children and just explain to them, and then they were totally different. They used

to come and offer to help you and, do you want your dog walked, or do you want messages or things. It all boils down to just ignorance.

By asking questions about people's impairments and why or how they acquired them, non-disabled people are reproducing the stereotypical presentations of disabled people in the media. If, as often happens in the media, disabled people are only seen in situations in which they are being asked to describe their impairments and the medical consequences of these impairments, it is hardly surprising that on meeting disabled people, non-disabled people feel able to adopt a similar manner to that of the media. The presentation of disabled people in the media extends the medical gaze beyond the clinic.

This invasion into other people's lives extended beyond asking about the impairment; they were seen as being incapable and untrustworthy, as Joyce describes:

Because it comes up time and time again. And I'll tell you one strange thing that happened. I took the bairns out to the pictures and it was a Saturday afternoon. I paid for the tickets and got them an ice-cream and somebody said to me 'Should you be out with the kids on your own?'

Not only are they seen as being incapable of looking after their own bodies and lives, but also of being unable to look after others.

Attention is also increased by physical barriers, by steps or heavy doors. Many talked about how, for example slopes or curbs made non-disabled people feel that they should step in and help, further creating the image that they are dependant on help from non-disabled people. This presented the informants with a dilemma. If it was a situation in which they could overcome they often felt patronised when people did step in, but, as Jose points out, it is difficult to know if you might need help in the future:

But even when they are condescending you say thank you very much but I'll manage. It was very kind of you. Because you never know when there'll come a day when you will need somebody to help you.

Engaging with non-disabled people

Many of the participants talked about the way that non-disabled people had difficulty to, or where embarrassed by, or scared of, talking to them, so Deirdre says:

Deirdre:they have backed off because I have spoken and the person with me hasn't, it is almost to say it can talk, it talked to me.

NW: Do you think you scare people.

Deirdre: Well, I think the wheel chair scares them.

NW: Why.

Deirdre: As I said before, they see the chair before me so it might scare people that I have actually got a voice and I can speak for myself because a lot of people don't see disabled people like that.

This need to educate non-disabled people was something that came up throughout all the interviews. As this work was funded by the Health Education Board for Scotland, I included a section on health education in the interviews. A number of the informants felt that one of the roles of health education should be to challenge the way that non-disabled people view disability. As Jane argues:

Jane: I think there should be more done with changing attitudes and things.

NW: Changing attitudes?

Jane: Yes, yes. There is not enough about disability at school or anything. I mean I never got taught anything at school.

The issue of segregated education was also seen as being at the root of what was termed the ignorance of non-disabled people. Deirdre described how, after going through segregated primary and secondary education and then moving on to a segregated residential college for four years post school, she knew little about life outside of institutions. This was brought home to her when she moved into mainstream further education:

Deirdre: It took me a long time because I went on a course in -----, it was for able-bodied, you know, and I was the only disabled person on it. And that was difficult because they had their own wee cliques and stuff, I wasn't involved in them for a long time.

NW: Do you think that's because they didn't want to know you ?

Deirdre: They didn't know how to speak to me.

She went on further to describe them as ignorant.

Oppression as Ignorance

The notion of 'ignorance' was used by almost all the informants to defend the comments of non-disabled people, as if they didn't really mean what they were saying because they didn't really understand what it was to be disabled. For example when I asked Javid how he felt about the people who had treated him like they did outside of the theatre, he replied "*They're just ignorant, they don't understand. It's just down to ignorance*" As Joyce argued:

How can I put it? I don't know whether you have seen it, but there was an advert on the telly recently about ... the television ... pouring the kettle with your feet and that. I was at the dentist in Duncan Street and the ... on the video on the waiting-room - they have things like they have in the doctors' surgery - and there was a couple of able-bodied in the waiting-room and I was just watching this room ... and they said ... 'Isn't that marvellous?' and I thought to myself 'What's marvellous about that? She's just doing day-to-day things like everybody else would?' So I said to them, I turned round to them 'I'm sorry but I couldn't help hearing you'. I said 'Why do you think it is so marvellous?' And they gave me a definition of it which was quite good. 'I have never come across a person with that disability. If only doctors and that told you more about certain conditions, they would be interested'. So then I thought "That's a good answer, it was an honest one from them and I thought, you know, perhaps we do need to do that."

This idea of prejudice as a result of ignorance was, in many accounts, supported by the informants' experiences with friends. Many argued that on first meeting them they could, by the force of their own personality, persuade non-disabled people that they were 'normal'. Jane put this eloquently:

Well you've got to prove to them that you're a woman first and you're disabled second. You're a human being.

Marion described how, in her view, non-disabled people needed to meet more disabled people if the discrimination that they faced is to be challenged:

Marion: I think if you've been brought up with people running around, going mad round about you, you'd have been able to accept your disability more and they would have been able to accept you, as a disabled person, more. I find this very

much with my niece and her friends - to her I'm just her Aunty Marion, I'm not disabled, and she has become very much more attuned to disabled people's needs, you know, because obviously she's around me. It's nothing for her to turn round and say, "Auntie Marion, there's somebody needing a hand," or, "There's a man dropped his stick, and she'll go and help them whereas before there's a possibility that would never have happened. People just looked at you and thought, "You're queer, and walked on.

Jane: So you think that if people aren't in contact with disabled people, it creates this barrier?

Marion: I would imagine so, yes. It's like if a person's never been in contact with death, they never know like it is until they're old, until it happens to their circle, they don't know what it is. Well it's just the same as a disabled person, the ordinary person, unless they have someone who's disabled within that circle, they don't know how to cope with it. Whereas if you took away the special schools and brought them into normal schools, I'm sure it would be a benefit in the end. I know there's some cases, like there's profoundly handicapped and the profoundly mentally handicapped might be a different story but on the whole I would say there's no reason why they can't bring disabled people in.

Ignoring Impairment

Whilst some non-disabled people felt that they were able to ask disabled people whatever they wanted, friends and family of disabled people sometimes found it very difficult to talk to them about their impairment. Many of the participants talked about how their friends or family did not ask how they were, as if they were frightened or embarrassed by the situation. For example, Holly described how, when she went to her son's graduation she was amazed that none of his friends knew that she was a wheelchair-user, *"It was as if he was too embarrassed by me to tell any of his friends."* Eve described how her father refused to acknowledge her impairment. Some of the informants talked about how they had to censor their own responses so that people didn't think of them as "moaners".

However, this reluctance to address the issue of impairment is sometimes used by disabled people to their advantage. Stewart told me how his friends never talked about his health because he didn't want them to. He wanted to talk about other things, not his impairment. He described how *"My muscular dystrophy was a non-discussible item in the household or*

anywhere, because I chose to treat it that way.” In this way he felt that he could ensure that his friendships were what he saw as “genuine”. As he puts it:

I am extremely lucky to have friends and they are not friends that are sympathetic, if you know what I mean. I have no time for sympathy. I have no time for friends who 'Oh I'll be friends with Stewart because he's got a disability' ... but the friends I've got are people who have known me with a disability, but not one that was a major problem in life. I have done all the things like staying with friends, driving all over for the best part of my life, and hell-raising too.

The fact that a disabled person has an impairment makes them visible. They are physically different and therefore more easily recognised. For example Leslie, who works in a large company, talked about how people who she didn't know often came up and talked to her, calling her by her name, expecting her to know them:

I was in the tea bar at work today and we've just moved to temporary premises because we're getting the roof fixed where we are and I normally go to the canteen and very rarely to the tea bar. I was at this tea bar, I think I've been there about twice since I worked in the place and I was waiting for a friend and I heard this voice saying "Long time since you've been here," "Eh" I said, "Yeah, I'm never down here." "Are you going to be about again" he said. I said to my friend "I suppose everybody recognises me." That's the point, I'm very recognisable. I can't remember everyone I have come into contact with so in a sense they're total strangers.

It therefore becomes impossible to hide, to become anonymous. She argued that disabled people will only be able to be 'ignored' when, or if, they become fully integrated into the mainstream and included in all walks of life. This was seen as essential to further the position of disabled people in society, so Leslie says:

Well the more society actually works towards having disabled people moving around as ordinary people with their lives, but not focus on the disability, the more you see disabled people out and about and on television, and things like that. What I'm trying to say is because they're managing director of a Safeways, not because they're chairman of SIA, the Spinal Injuries Association, that's all

necessary and it's worthwhile but all too often, people who are using up a lot of energy to try and promote the views of disabled people are working in that line anyway, and in a sense it's a bit of a contradiction, that somebody like myself holds me back from becoming more active than I am because I don't want my life to revolve around disability. I want to see disabled people who work in a clock factory or work in Safeways or work in a shop or a restaurant - I just want disabled people to be seen in the main stream workplace.

Ignoring or Challenging Ignorance

From this analysis it is apparent that the participants are made to feel both invisible ('does he/she take sugar?') and at the same time visible, in that they 'stand out from the crowd'. Whilst these may seem to be contradictory positions, the origin is the same; the denial of agency. When staring at an impaired individual, non-disabled people are objectifying that person, positioning the person as a disabled thing, a distortion. The depersonalisation in encounters denies the individual a place as a competent member of society, again positioning the person as a distortion.

Resistance to this objectification was achieved by one of four means. First were those such as Caroline who rarely went out, and when she did completely understood, and seemed to agree with the way that she was treated, offering no resistance. For example, when I asked how she felt when she was ignored she replied:

Caroline: It makes me feel a bit invisible at the time. In a funny way I can understand why they are doing that.

NW: Why do you think it is?

Caroline: I think they're doing it because it is their own insecurity and embarrassment of being disabled and just ignore you.

NW: Embarrassed about your being disabled?

Caroline: I think so.

VW: Are disabled people embarrassing?

Caroline: Yes.

NW: Why do you think they are embarrassing?

Caroline: I don't know. I haven't got a clue.

The second strategy involved engaging with, but ignoring the comments and stares of other people; ignoring ignorance. So Sandra said:

NW: *What do you do when people are staring at you when you walk down the street or anything like that?*

Sandra: *I walk with my head down.*

NW: *Do you? Deliberately?*

Sandra: *Pretty much, yes. I would rather not see them stare at me.*

This allows the informant to ignore the assault, but it is not denial in that she talked openly and knowingly about the way that people stared at her. By adopting this approach, one of silence, she is refusing to take part in the interaction. She feels that there is little point in challenging their perceptions and she can make a more powerful protest by ignoring them.

Third, informants such as Stewart confronted this objectification by the way that they dressed and held themselves. He talked about how he was always smartly dressed, "never a hair out of place" arguing:

When I'm in a suit people talk to me

This approach is one of active resistance, he is challenging the notion that he is a passive victim of either his biomedical condition or the society that refuses to give him his full citizenship. This is discussed more fully in chapter seven.

Fourth are those such as Deirdre who directly challenge the ignorance:

Well people that, if I'm with somebody and they're pushing me along the street, they'll ask the person that I'm with, like if I'm in a café and that, they'll ask the person with me, "Does she take milk, does she take sugar?" and stuff like that. And I'm sitting there, and I'll say, "I can hear you, you know," I end up saying something because it's really, . .

However, at times, for some of the participants, confronting the insult was too much effort. As one commented:

I don't want to turn every cup of tea into a disability equality training session.

For some these assaults served not only to remind them that they were different, but also as a means through which they could identify with other disabled people. Stella described how she was able to share these “challenges” with other disabled people, to laugh about them and how they acted as a “catalyst to change....the other thing that does for me because of the relationships I have, is to actually stimulate and challenge and say 'Let's change this'.” She takes a very political approach to these insults, seeing them as a device around which she and like-minded people can organise to resist their representation. It is through prejudice and other forms of discrimination that a collective can be formed, one through which she can draw strength.

Ignoring Sexuality

Whilst there were gender differences in the data around the different ways that men and women experienced prejudice in relation to their sexuality, there was a common theme of downplaying or ignoring the fact that the participants were sexual by others. The men described how, in their encounters with women they were seen as essentially asexual. Some turned this to their advantage, such as Drew who described how he was able to build up a better relationship with women at work

It gets a lot of the crap out of the way. I want to believe that I'm one of these new men so I want to go through life without having to deal with all this nonsense. If I want to engage in sexual activity then that's what I want to do. If I want to get a report produced then I don't want to have sexual politics get in the way.

For other men in the study this was problematic. John described how he was having trouble with one of his female personal assistant's, who walked round the house in a state of 'semi-nakedness'. He was unsure whether she was teasing him, leading him on, or whether she just thought that he had no sexual feelings and so would not be bothered by whatever she wore. Keiron talked about how he felt that women viewed him as a medical case, and knew more about “what caused cerebral palsy than what made me as an individual tick.” He talked about how he had been unprepared for any feelings he might develop, that no one had spoken to him about this:

Well I think it's difficult from the point of view that because of the places that I was educated at and brought up in, nobody really discusses the fact that there's going to come a day when you're going to experience things and emotions and your

body is actually physically going to change. Because, as I was saying before, I think this attitude that you're always going to stay in a home. I think that's the kind of attitude that prevails, and a lot of the things that you learn, you don't learn as much as through trial and error.

Professionals therefore serve to reinforce the notion that disabled people are not expected to have sexual feelings. Archie, for example, only learnt about the drug papavarine² through talking to other paraplegics.

I wasn't told about that, and what you could do sexually, and I think they were... they shied away from that as well, the doctors. They didn't, at that time, in my experience, they didn't talk about it. If you wanted to approach the subject you had to broach it. They didn't approach it for you. And I never spoke to any social workers, or health visitors, or anybody like that, that specially dealt in these areas that could tell you about it. Nobody told you about it. You heard about it through disabled people. Most things you hear are through disabled people.

His last point was echoed by many. Some felt that it was because professionals were too embarrassed to talk about sex, whilst others felt that it was because they were seen as having no sex lives. This affected the confidence of many of the participants as they approached their adolescence and early adulthood. As Mark says:

I think as an adolescent, I didn't really have any sexual experience, I mean I think girls at the age of 14, 15 probably even up to 19 or so, maybe even later, tend to look at a wheelchair and think, what would my friends think if I'm seen with someone in a chair. And I don't think I ever had a girlfriend, partly I think that was a lack of confidence on my part but I think there is a certain amount of restriction because people do look at the chair first, especially when they're younger.

Some also talked about how, in their past, they would hold back from forming a relationship, afraid that if it developed into something physical they would not know what to do, or how the woman herself might react.

² Papaverine is a drug used in impotence.

These feelings serve to again remind the disabled person that they are seen in some way as different. But not all informants felt like this. As Arnie says:

I try not to let it, but obviously, the degree of disability, I'm not sure how it would affect me if I wanted to have children. Not having a girlfriend at the minute, it's not really something that I've thought about, but if the right person came along, I'm sure these little things would sort themselves out. But being disabled doesn't really affect my male image. And anyway if I want to go out with a girl, I will do. I'm not going to let a wee thing like being in a wheelchair get in the way.

Arnie himself had never had a partner, but, as he said, felt that it was only a matter of meeting the right woman. Only one male, John, felt that his impairment affected his ability to form relationships. He has never had a partner and wondered whether this was because he was disabled. It seemed that for most of the men, whilst recognising that there were difficulties, there was a belief that they could, if the conditions were right, form a relationship.

The whole basis of an individual's relationship was also challenged by non-disabled people; as if anyone choosing to live with them did so out of compassion, rather than love. So some of the male informants talked about how their partners had been described as angels because they choose to live with them. It appears that disabled men are seen as damaged property, as not worth living with, so Drew says:

A lot of people are surprised that Sarah and I met after my accident. The presumption is that Sarah and I have been married for a million years and that something tragic has happened to me and Sarah stuck with me. Love, honour and obey and all this crap. Just a flicker in the eyes, how can a perfectly rational, nice, intelligent woman actively choose to form a relationship with somebody who is as broken and helpless as he is.

Bob talked about how other people had been unable to accept his partner as other than a friend:

My partner has a disability but I won't go into that while she's not here but she has a disability herself and I have a disability and everybody thinks how sweet, they're company for one another! You know, this is what we get all the time, Bob's got a new friend, isn't it sweet, and they're staying together, they'll be company for one another. ...They don't realise all the things that go on. This is what

they imagine: Romantic, nice, poor wee fellow. Pat his head, look for the hole and put a shilling in.

Archie, describing an incident in which his wife was praised for choosing to live with him, shows how he not only resists this assumption, but that he and his wife have renegotiated their relationship from what may be described as traditional.

He said you have an awfully good wife, and I said what do you mean, he said, well, taking you on in getting married and I - well I never lost the head but I raised my voice and I said what do you think you are talking about son, I am just like anybody else and she doesn't have to help me with anything. I look after myself. I don't have to have her look after me 24 hours a day. You say that to an able bodied guy who batters the shite out of his wife while getting his wife to run after him, you tell me my wife is great because she is looking after you. And he changed his attitude, he got a shock and after that he just shut up after it. That is just one experience. My wife as well she would tell lassies at work that her husband is in a wheel chair and they were all shocked but they all sort of love me, amazed how I am an independent guy and when they talk at the work they can ken what Mandy does, she doesn't have to do anything, her man cooks the meals, does the ironing, does the washing, does everything, she doesn't have to do anything when she comes in the house. And you get other guys who are not working and who don't get off their backside, I know lassies are quite shocked, and other lassies will tell them straight it is not like that.

Wilber's partner was seen by her friends as fortunate, in that her husband looked after their child, allowing her to pursue her career without having to worry about childcare arrangements. Through this re-negotiation of the traditional male role these informants challenged the idea that they did not contribute to the relationship, but it is the very fact that they are called upon to justify their contribution that can serve to remind them that they are different.

For the female informants slightly different issues were raised. Again many of them were de-sexed, seen by both professionals and other members of the public as people who had no sex life. For example Deirdre described how, when she had a home visit from the DHSS about her benefits, they refused to believe that she could be living with her then partner as a couple, despite living in a one-bedroom flat. Whilst this may have been advantageous in that her benefit would not have been cut, she felt that she had to challenge this and when she did so was

made to feel that she was causing problems. Similarly Eve told me about how she felt that she was now unable to have a boyfriend

NW: How do you think your disability affects you as a women?

Eve: Boyfriends are out.

NW: Why do you think they are out?

Eve: Nobody looks at you.

NW: You don't think people look at you?

Eve: No more.

NW: No more? Why?

Eve: You tell me. I just feel that before everything happened things were good and boyfriends were on the scene and marriage was on the scene and everything changes when your health goes.

Further, many of the women, in contrast to the men, talked about their appearance. The presence of an impairment was seen as a mark of difference which they felt excluded them from what may be described as gender normal roles. So Leslie says when I asked her how she felt about how her disability affected her as a woman:

Well it's dramatically changed meeting up with guys and things like that - that virtually has not happened since I've become disabled. I've had one boyfriend who was disabled himself, and that's how we met, through having a disability and being in the same hospital. And other than that, ok so I'm getting old and life has changed in that respect too. Pre-25 I was out at a lot of clubs and things, and pubs, out with a bunch of single girls, and eating out with people and all this kind of thing. Now I would say, friend-wise, anyway, a lot of my friends tend to be married and things. Actually I didn't have a big friend base here having been abroad for a long time. And my friends from University were language students too and they've all moved away. So the opportunities to meet people, I mean I go out

a lot but it tends to be for meals and so on. However if I am out at parties and things and I do meet males and have a right nice time and I'm sure they think I'm a really nice person. If it's somebody I get on with. But never in a million years would it enter their head to take things any further. However I'm a person who believes that you never know what's round the corner, and I've come across disabled people who have met people, but you are treated differently, definitely.

The ignoring of sexuality by others is, again, central to this account. But it is different to that of the men, in that these women felt that they could not even start a relationship whilst most of the men talked about how they could if they so wished. Stella took this even further and described how growing up with an impairment had affected her sense of what it was to be a woman:

NW: How does your disability affect you as a woman?

Stella: I find that hard to answer now, but I could answer it if I think back to when I was a teenager because I guess I had a very - as most teenagers do anyway - a very ... no idea of who I was. A part of that was about what others' perceptions of my disability would lead them to suppose; in other words that, for example, because I presumed, rightly or wrongly, other people saw disabled people as sexless, then for me that was a real attack on my femininity, on my womanhood as I grew up. Now I have kind of thrown that off and it doesn't matter two jots to me.

She described how, for a time she herself had almost denied any sense of sexuality, and that it was only through contact with other disabled woman that “*lead us to relax and be comfortable in ourselves and therefore to express that comfort in our relationships with non-disabled people*”.

Some of the female informants directly challenged this type of categorisation. For example Jane replied, when I asked her how her disability had affected her as a woman:

Well I've been married twice; I've had two children. You get the odd man who just wants sex with you because you're disabled, because they're perverts. But on the whole they accept me as I am, not because I'm in a wheelchair. I mean I'm a person first and disabled second and if they can't accept that I don't want to know them.

Jane's approach is different to many of the other women interviewed. For her life was a political struggle. For example, when she talked about raising her family, she said:

Well I brought my son and my daughter up on my own, because my husband died when my daughter was 2 years old of alcohol poisoning. And I had to prove to everybody - it wasn't because I was in a wheelchair, couldn't be looked after. The health people were never away from my door and then it got that they were coming to me and saying, "You've managed to do it, could you help so-and-so and advise them."

Jane resists her position, rejecting any notion of subordination, either on the grounds of her gender or her impairment. Similarly, Joyce, whilst acknowledging that having an impairment affected the way others saw her as a woman; "*They don't see you as a normal human*", took a similar position when she attempted to undergo assisted conception:

Now, I've always expressed to the doctors that I wanted my own family. When I went up to the Western General to meet the doctor would be in charge of me if I was ever pregnant, the whole experience of that was strange, because they saw my disability in medical terms I told them my wishes and she said 'You can't really be serious about this?' And I thought, why not? 'Because, she said, 'you've got all... and yet you want to bring another life into the world' and the thing was totally strange.....She saw my disabilities before she saw the person if you like and that really astounded me, especially when she deals with disabled women and pregnancy all the time. It really astounded me. I went back to my GP and she took me aback when she said that, but I just expressed that I really wanted it and I was going to pursue it. In the end my doctor sort of smiled at me that I had told them I was still going to pursue it. She didn't put me off.

What is also striking about this is the way that Joyce, as a disabled woman, is questioned about her suitability as a mother, yet neither Wilber or Archie who both sought advice about assisted conception, were questioned in such a way.

What is interesting in these responses is how, for all of the women I interviewed, there was no attempt to renegotiate what it was to be a woman, as many of the men had done. What comes through clearly in the data is what Connell (1987;183) terms the 'global domination of men over woman'. Women such as Jane, who whilst they are able to argue that their disability has not affected them as a woman, cite as evidence their ability to form relationships with men and their ability to raise children, all gendered roles. Unlike the men, such as Archie or Tommy,

she appears unable to reformulate the role of woman, she attempts to meet a stereotypical image of womanhood, that of partner and mother. Archie has been able to challenge the stereotypical image of masculinity, that of provider, and to moderate what it is to be a man.

Conclusion

This chapter has presented data on the participants interaction with other, non-disabled people. It started by examining the importance of social interaction in the creation of oppression and argued that it is through interactions that people become aware of their impairment. That is social interaction can make the body *dys*-appear.

The data presented showed how, in their day to day interactions disabled people are made the objects of physical assault or abuse, ignored, treated as children, patronised and denied agency. The informants also talked about how they were not treated as sexual beings, how their relationships were downplayed. These are the daily experiences of oppression. Not only does this serve to remind the participants that they are different, but it also removes control from their lives. That is, through interaction with others the participants learn that they are not deemed able to make decisions for themselves, that they should relinquish such notions and hand over control to professionals, people who 'really know how to tackle the everyday problems that disabled people face'. Prolonged contact with individual professionals does allow for these actions to be challenged.

The informants were not passive in the face of this oppression and often challenged it. These challenges took many forms including the way that the informants presented themselves to others, directly challenging the oppression, ignoring the insult or withdrawing from social life so as to reduce the possibility of being insulted. This did impact on their lives as, in day to day interactions with other non-disabled people, challenging oppression can become tiring.

The chapter also described how many of the informants thought that non-disabled people were uncomfortable talking to them. This, they felt, was the result of segregation in education. That is, they felt that through a process of assimilation, the difference that others perceive between disabled people and non-disabled people would disappear. Not only does this serve to let the perpetrators of the hook, it also reduces the impact on the disabled person. It suggests that non-disabled people are behaving in a socially determined way, that their views are a consequence of social structure and that by educating them they will be able to throw off their preconceptions about disabled people. The informants were, in a sense, othering non-disabled people, arguing that, because of their poor understanding of what it is to be disabled, they could not hold legitimate views on the subject. Whilst not condoning the prejudice that they experience, it is excused, denying that non-disabled people are oppressive. Prejudice is thus

depersonalised. It is seen as a technical issue, a lack of knowledge, removing agency from the oppressors.

However, in spite of these comments and experiences, many of the informants were able, as the last chapter showed, to create a sense of embodied being that ignored both their impairment and other people's attitudes to their impairment. It is this creation of identity that forms the basis of the next chapter.

Chapter 6

Identity Claims

Oppressed people resist by identifying themselves as subjects, by defining their reality, shaping their new identity, naming their history, telling their story. bell hooks (in Shakespeare et al 1996).

Introduction

The next two chapters explore the themes of identity and identification in the informants' accounts. They are closely linked and there is some overlap between the two chapters and, at times, the separation between the two chapters is artificial. The separation is primarily for presentational purposes. This chapter focuses on issues of self-identity and is grounded in the informants' accounts around their own self and identity. It starts with a brief description of what Hall (1996) describes as the two main schools of thought on identity. It then moves on to explore and discuss the self and the embodied nature of self and then explores the place of identity in disability studies. The research participants' accounts around self-identification are then presented. The analysis of the data suggests that many of the informants do not see themselves as disabled and do not identify as disabled people. The political consequences of this are briefly examined. The views of those who identified as disabled are also explored.

Theorising Identity

The concept of 'identity' has become both a contested and a prolific field of research and theory in recent years (Hall & DuGay 1996). Hall (1996) has suggested that within the social sciences there are two historical and strategic approaches to the production of identities. The first model is based on the assumption that there is an essential, natural or

intrinsic meaning to any identity. This identity is based on either a shared social experience, origin or structure. An example of this approach is found in the work of feminist theorists such as Hartsock (1990) and MacNay (1992) who promote the notion of a female subject and hence a female identity to form the bedrock of feminist politics. Much of the writing on disability from within disability studies falls within this paradigm. The second model denies the existence of any identity based on a shared origin or experience. Identities exist only as opposites, they are multiple and temporal and to propagate the concept of for example, a male and female identity or a disabled and non-disabled identity serves only to strengthen essentialist arguments.

To writers such as Butler (1990) and Fuss (1989), whose writings fall into the second category, the project of feminism and other emancipatory movements is to undermine any concept of identity or self. Within this paradigm disability or impairment cannot serve as a foundation as these are empty and constructed. Applying a category as a foundation or as fundamental to political claims can only result in political closure: so Butler, from a feminist perspective, writes:

When the category is understood as representing a set of values or dispositions, it becomes normative in character and hence exclusionary in principle. This move has created a problem both theoretical and political, namely that a variety of women, from various cultural positions, have refused to recognise themselves as 'women' in terms articulated by feminist theory with the result that these women fall outside the category and are left to conclude that (1) either they are not women as they have previously assumed or (2) the category reflects the restricted location of its theoreticians and hence, fails to recognise the intersection of gender with

race, class ethnicity, age, sexuality, and other currents which contribute to the formation of cultural non-identity (1990;325)

For Butler, identity is constructed in relations of discourse and power. Fixed identities of sex and gender are enforced through a regulatory regime of heterosexuality. Similar points in relation to disability have been articulated by Liggett (1988), as discussed in chapter one. However, whilst this approach appears to leave room for agency in that discursive practices are embodied in the performances of human actors, its insistence that identity is constructed through discourse serves to suggest a more deterministic process for identity formation. In Butler's work there 'need not be a 'doer behind the deed' but that the 'doer' is variably constructed in and through the deed' (1990; 142). The self is a performer, but there is no self behind this performance (Benhabib 1992). Identity emerges solely through discursive means and there is no space for reflexivity. Discourse serves as a means of social control and symbolically inscribes with meaning and significance and through this identity emerges and is sustained. There is no possibility of escaping linguistic construction (Butler 1993; 10). There is little room in Butler's work for an understanding of how identity forms, how selves are constructed by others and construct themselves. Such an understanding requires the presence of a self, a 'doer behind the deed' (Dunn 1998)

Self

Self is an unformed, unfixed concept (Giddens 1991) and is, as Mauss (1989) argues, constituted both as an evolving concept (which is social in origin) and as a universal sense (which is not social). This universal construct of the self is the product of the fact that 'there has never existed a human being who has not been aware not only of his body but also of his individuality, both physical and spiritual' (Mauss 1998;3). The universal

self is a pre-requisite for the existence of a social self; the social self is embodied within the medium of the universal, biological self. Much of the sociological theorising of the self has tended to distinguish between these two concepts giving primacy to the social (Turner 1996;67). The role of the body in the creation of identities, the social ascription of role and its political implications have tended to be ignored. We act through our bodies upon our world and it is through our bodies that we experience and comprehend the world (Schutz 1971)

The work of Mead, James and Connolly have been especially influential in this school of thought. It is premised on the notion of human individuality. Human beings are consciously aware of their own lives and it is through reflexivity that we become aware of a consciously constructed self (Dunn 1998). The self, it is argued, arises as a result of self-objectification, the process of seeing oneself as others see you. As Giddens puts it: 'Self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. It is the self as reflexively understood by the person in terms of his or her biography' (Giddens 1991;53)¹. The self becomes constructed through discourse, it is produced in specific historical and institutional sites, it is the product of more or less rationalised schemes which shape our way of understanding; the self is an historical construction based on our biography (Taylor 1989; Giddens 1991). Self is the product of culture, providing individuals with an identity, so Taylor writes:

My self-definition is understood as an answer to the question Who I am. And this question finds its original sense in the interchange of speakers. I define who I am by defining where I speak from, in the family tree, in social space, in the

geography of social statuses and functions, in my intimate relations to the ones I love, and also crucially in the space of moral and spiritual orientation within which my most important defining relations are lived out. (1989;35)

Modern-day theorists of the self such as Calhoun (1994), Giddens (1991) and Taylor (1989) take a much more embodied view than that of the earlier theorists. In contrast to, for example Mead, who asserts 'We can distinguish very definitely between the self and the body' (1962;136), Giddens argues that the self is embodied and that it is through the body that we become aware of the self (1991;56). More importantly, in the context of this work, is Giddens assertion that

Routinised control of the body is crucial to the sustaining of the individual's protective cocoon in situations of day-to-day interaction.....routine control of the body is integral to the very nature of agency and of being accepted (trusted) by others as competent. (Giddens, 1991, 57-57)

This focus excludes people whose bodily competence is compromised, for example (in the dominant medical discourse) disabled people².

¹ There is a tendency to conflate identity, self and self-identity, often using the terms interchangeably (Lemert 1994). For example Strauss and Corbin (1987) refer to self as a matter of personal identity 'who I am over the course of my biography' (p252).

² It could also be argued that other groups - for example, women, due to pregnancy or menstruation, or older people, or those who have responsibility for small children, and who experience lack of bodily competence by proxy - are compromised in this approach. Moreover, central to many contemporary social rituals and interactions - for example social use of alcohol and narcotics - is this process of self-compromise (interestingly this connection is emphasised by vocabulary such as 'paralytic', 'blind drunk' and 'legless'). (Shakespeare and Watson 1995)

Self is therefore seen as a universal human property, something that we must all possess and a characteristic that we must all develop (Lemert 1994). Under the influence of Giddens and others, and in sharp contrast to the ideas of Butler discussed above, theorising on self within this school of thought has become colonised by reflexivity; who we are, who we choose to identify with, what we choose to do are more often experienced as matters of choice. We learn who we are not by concrete relationships within a physical community, but through abstract symbol systems. Group membership is no longer synonymous with identity formation. We are, according to Giddens (1991) able to choose our identity and can ignore or reject identities fostered on us as a result of ascribed characteristics. We do this by the creation of narratives about the self, and provided we can sustain these narratives we are able to maintain our sense of self (1991;54).

Through this approach the problems associated with conflating identities into essential, fixed, pre-ordained, singular categories, for example the homogenisation of disabled people into a singular group and the ascription of a single identity, can be avoided. Our sense of self is constantly evolving. We constantly reconfigure ourselves through multiple identities, and time space and relationality are all important in identity formation. As Somers writes:

...it is through narrativity that we come to know, understand and make sense of the social world, and it is through narratives and narrativity that we constitute our social identity.all of us come to be who we *are* (however ephemeral, multiple and changing) by being located or locating ourselves (usually unconsciously) in social narratives *rarely of our own making* (1994;606).

She further argues that what we do and how we do it are the result of cross-cutting relational story lines in which we locate ourselves. The notion of the self is therefore embedded in shifting networks, or 'webs of interlocation' (Taylor 1989). However, sociology, as Somers (1994) argues, with its focus on epistemology, the standards we use, the way we understand the world and what we use to legitimate these foundations places little emphasis on ontology, on problem formation and on social being. Research is on action rather than representations of being. Somers argues for a rejection of a decoupling of ontology and action, and an incorporation of social being and social identity into action, agency and behaviour. By so doing social agency is brought to the fore and the notion of self and identity take on a political element as it involves 'refusing, diminishing or displacing identities others wish to recognise in individuals' (Calhoun 1994;21).

Somers is arguing for a focus on what she terms an ontological self, a sense in which the self becomes embodied, a mode of being in the body, of living the body. This is in contrast to what she sees as the epistemological self a sense of knowledge about the self derived from others, a disembodied self, a self away from the body although the result of the body. Her call mirrors a growth in writings in which oppressed groups rewrite their past and present in a more positive, self assertive vein. For example the Black American feminist writer Patricia Hill Collins, asserts that:

By insisting on self definition, Black women question not only what has been said about African American women but the credibility and intentions of those possessing the power to define. When Black women define ourselves, we clearly reject the assumption that those in positions granting them the authority to interpret our reality are entitled to do so (1990;106-7)

As the last chapter showed, the informants in this study shared one important attribute; they were all made the subject of oppression. Whether this acts as a categorical classification for disabled people as a social category, or whether disabled people themselves identify in such a manner is not known. Do disabled people know who they are because of the fact that they have an impairment, because of the fact that they face discrimination or because of who they, ontologically, believe themselves to be? These are fundamental questions in any analysis of disability. How the identification of disabled people is explained in disability studies forms the basis of the next section of this chapter.

Identity, the Self and Disability Studies

Identity and notions of the self in disabled people have aroused a great deal of interest in medical sociology, especially amongst those who write in the interactionist tradition. For example, Goffman's (1963) analysis of 'spoiled identity', *Stigma* and Scott's (1969) *The Making of Blind Men* brought issues of impairment and identity into the sociological mainstream, and such writings have been influential in the work of, for example Kelly, (1992. 1996) and Pinder, (1995), Williams (1984). However, much of this work concentrates on the effect on identity and self of impairment, the emphasis being on the need for adjustment to loss, coping and mourning (Shakespeare 1996) According to Gerhardt (1989), these writings fall into what she terms a 'negotiation model', and contrasts with those who write from a 'crises' model perspective. As discussed in chapter one, people who have an impairment or chronic condition, it is argued, suffer a loss of self and go through a process during which they negotiate their lives in such a way as to be as ordinary as possible and so retain some contact with desired life-worlds.

However, in disability studies, identity and self have tended to be viewed through an analysis of oppressive social relations with the focus on changing society and empowering disabled people (see for example Barnes' (1990) analysis of the socialisation and identity formation of young disabled people). Shakespeare (1996) makes the point that it is in the area of identity that conflict between disability studies and mainstream social science is at its most virulent.

Disability identity is important, as Shakespeare (1996) argues, because it is through identity that an understanding of the complex relationship between individuals, society and biology emerge. For those writing from a Disability Studies perspective, and those working within the Disabled People's Movement, identity as a disabled person is presented as something fixed, or stable. It is a shared experience based on common interests (Finkelstein, 1993; Campbell and Oliver, 1996). Linton (1998) has suggested that Disability Studies itself has arisen, in part, from an attempt to be clear about what disability identity really means in a social world.

In much of the writings on disability that have emerged from disability studies, identity is presented as unproblematic. So, for example, Oliver sees disabled people as identified through three key elements:

- (i) the presence of an impairment
- (ii) the experience of externally imposed restrictions
- (iii) self identification as a disabled person (1996;5)

Identity for disabled people is therefore, according to Oliver, ahistorical, unsituated and decontextualised. Most writing about 'identity' tends to place emphasis on self-definition and/or social definition in terms of language. It is interesting that in both accounts it is assumed that disability identity exists prior to language, and is simply 'marked' or 'reflected' in how disabled people come to use language (Corker 1999a). This is not to deny the category 'disabled person' but to argue that such a classification must be historically situated, socially composite and seen as part of a multiple identity.

It is almost as if Oliver is suggesting that disabled people have a collective 'one true self'. The experiences of disabled people are historically situated. To be disabled now is different to the experiences of disabled people in the past. Bourke (1996), for example, documents how the returning war wounded of the first world war were treated with a respect that had previously been denied to disabled people. Recent pronouncements by the embryologist Robert Edwards (Rogers 1999) on what he describes as the 'sinfulness' of parents who choose not to have a foetus with a known genetic abnormality terminated may suggest that in the future any such child will be treated in a different way to how it is today.

This is not to say, that the notion of a shared identity has not played a crucial role in the development of the Disabled People's Movement and the on-going political struggles. It has been, and hopefully will continue to be a powerful and creative force, and is, to a large part responsible for the emergence of the new representations discussed earlier. Whether such a shared identity exists, however, has not been explored. There is an assumption in much of the writing on disability that what Somers (1994) would term an epistemological self, that is a self that is created through knowledge about the self built up from others opinions of the individual, predominate in constructions of the self. In the

same way that Fraser and Nicholson (1990) argue against appeals to the unity of women to justify feminism and feminist politics, so there is a need to document experiences from a variety of disabled people. Collins (1990) in her monograph on what she terms Afrocentric feminist thought, argues that knowledge is socially anchored in experience and that multiple social standpoints produce plurality of knowledges, each of which is partial. Through multiple oppressions, Black women learn to rely on their own experience to survive. It may be argued that disabled people adopt similar strategies in their own constructions of their self, consequently, feelings and personal values carry broad political and social implications and these feelings and personal values need to be explored. This next sections present an analysis of the data. It explores the informants accounts of their ontological self; what is it that they think about themselves, their own construction of identity and how, through these constructions, they survive. .

The Rejection of Impairment in Construction of Self-Identity

As the previous chapter showed, the informants in this study experienced civic and social disenfranchisement and violence. This is experienced in addition to the cultural representation of disabled people as abject (Heavey 1990). Yet, despite these daily experiences of prejudice, only three of the participants had what may be termed a purely negative view of themselves. For the vast majority of the participants in the study, impairment was not seen as important to their sense of identity or self. This resistance to cultural perceptions of disability and a rejection of impairment as a central characteristic took a variety of forms. Firstly were those such as Arnie, who, through their accounts suggest that their physicality did not produce a difference between themselves and nondisabled people, challenging the universal 'biological' self:

NW: When you think of yourself, what image comes to mind?

Arnie: A normal person. The only difference is I'm in a wheelchair, and I try not to think of that as a difference.

NW: You don't think of that as a difference?

Arnie: No, I'm equally capable of competing with an able-bodied person.

NW: In what way?

Arnie: In jobs, in socialising, mixing with the opposite sex.

NW: How do you think your disability affects your view of yourself?

Arnie: It doesn't.

NW: It doesn't affect your view of yourself?

Arnie: I'm equally as intelligent as any able-bodied person and equally as capable of doing things as an able-bodied person.

For Arnie then, the presence of an impairment is not reported to affect his sense of self, he is as he describes a 'normal' person and there is no attempt to incorporate his impairment within his self. Whilst he states that because he is in a wheelchair he is different, this difference is negated. For many who took this view, any differences between themselves and nondisabled people were simply the result of discrimination and

prejudice. For example Archie, after describing himself as normal, and noting that the only difference between himself and non-disabled people is that he uses a wheelchair, goes on to say:

I try and show them that I can do just as much as what they do, if not more, apart from the obvious things like, with them being able bodied, that they can climb up stairs, and they've got better access to places because they can walk up stairs or they can climb up a hill or get a bus, or get on a bike or things like that. But I show them that that's the only difference, really, is the physical difference, cos they can use their legs and I can't. That's the only difference, is the access, because of society, that they don't really make enough access for people in wheel chairs. But apart from that..

Physicality is therefore sidelined, self-identity rests in what Archie is able to do and not how he does it, and if it can't be done it is because of societal and environmental barriers, rather than the result of an impairment. He does not want to be othered on the basis of impairment, demanding a different way of defining normal and other. The sense of self is a sense of knowledge about the self, and whilst the self is of course embodied, in that it is through the body that Archie is able prove to others that his identity is not determined by his impairment, identity is disembodied. It is a self 'away' from the body. Importantly though, there is no denial of impairment. Archie is therefore able to define who he is by what he becomes as a result of his actions. His self-identity is not immutable. He is allowed a dynamic analysis of what others think about him and he is able to transform the structure and content of what others say. Self can therefore become a struggle, as Archie confronts others, challenging their meaning. Self is thus a product of self-determination, autonomy and choice. It is his will that creates the self but in

interaction. In other words, the creation of the self becomes a symbolic work of constitution. It is Archie who decides what is symbolically important in his self-identity, by rejecting how others may see him and, through an interpersonal and social process challenging the narratives about him, he can adjust the ideas of others to fit with his own idea of his self-identity. By confronting 'disablist stereotypes', which he sees as negative and demeaning, he is able to present a picture of himself as an active, resistant agent. Self-identity becomes a political issue.

However, this political identity is not an ascription of identity on the basis of group membership. Identity politics, as writers such as Calhoun (1994) and Philipson (1991) describe is premised on the notion of a singular identity based on a set of ascribed characteristics through which individuals claim membership of a group distinct from the rest of society. Identity politics involves a preoccupation with group membership, a group that the members must see as clearly demarcated, with group boundaries a necessary definition of the self (Philipson 1991). Self-identity and subsequently agency, for Archie is achieved through a practical demonstration of his skill and abilities and it is through this agency that he is able to reaffirm his own sense of biography and challenge identities ascribed to him on the basis of his impairment. Identity for these informants is more about the rejection of group boundaries than their reaffirmation and the presentation of the self involves a rejection of difference. Mark made this clear when he stated:

I don't tend to think of myself as disabled, you know I don't think, oh I'm in a wheelchair, disability's a major part of my life.

Identity is about establishing a sense of unity between themselves and nondisabled people. It is about overcoming the paradox of having a different body, one that is used by many people to ascribe characteristics, but at the same time rejecting this sense of bodily identity. It is also, however, not a self-identity posited on the post-modern values of diversity, heterogeneity, eccentricity and otherness as described by for example Butler (1990) or Young (1990). Archie demands that we think beyond the dualism disabled-nondisabled, his sense of self emerges through the product of a life narrative. It is a reflexive process.

This description of the self was performed by many of the participants. Joyce, for example, argued that she was not primarily a disabled person, and that her identity was the product of relationships, relationships with people or with groups of people and the social roles that she performed within these relationships:

Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person. I see me as an ordinary person, sort of being a housewife, being an Auntie, just doing ordinary things that ordinary people do.

These relationships structure her self-identity. If this is accepted, then it has to be acknowledged that identity formation for disabled people is not a unique experience contingent on the presence of an impairment, as some writers seem to suggest (for example the work of Charmaz and Bury), but is part of the experience of identity formation common to people as much research has shown (Mellucci 1996).

Furthermore, for Joyce, being a disabled person was not only not seen as an insignificant part of herself. It was quotidian. Impairment is part of her everyday experience. She is

just a person with an impairment. She feels normal. She is normal, and the awareness of who she is, is not premised on who people think she is but on what she feels herself to be. For example she described to me how annoyed she got when other, nondisabled people failed to see this:

That really gets my goat. You know, when you are trying to live a normal life and every time you achieve something they sort of pat you on your head and say 'Ain't that good?' and you don't need that. I mean to them it's wonderful because they have never had the experience but to you it's nothing out of the ordinary.

This idea of normality, of leading a normal life, of just getting on with things was present in many of the participants responses. For example Deidre talked about how people often told her that it must be hard for her to achieve things and said 'I don't find it too hard, I just get on with it'. Being impaired is a fact of life for many of the informants, it is an everyday condition and as such does not impinge on their sense of self.

For some of the informants, this was because they had always been that way; they had been born with an impairment and had no knowledge of life without an impairment. For example, John told me how he often used to try and imagine what life would be like if he had not had an impairment, but could not. It is almost as if it is a phenomenological impossibility for him to imagine what life without an impairment would mean. John's image of himself was not as a disabled person but as someone who was 'Going bald with a good sense of humour'. Throughout their lives, these particular informants had created a biography that incorporated their impairment into their sense of identity in such a way as to normalise the impairment. This is what Somers (1994) would term an ontological self. As Jane says:

When I was a wee girl I used to pray every night that just for one day I could walk. I would have danced the soles off my feet. And I could never accept this not being answered. Now I do, I realise it's not meant to be. Then, if any able-bodied person came into the children's home I'd always get round behind them to see where the key was. I couldn't understand how they could walk without crutches, sticks, callipers, so somebody had to wind them up in the morning, somewhere there had to be this key that turns. That's how I looked on it. But as I say, I don't know if I could accept being able-bodied and then struck down with a disability. Maybe you're lucky because you've known what it is to be able-bodied. Maybe I'm lucky that I've never known anything else, I don't know. But I just don't see myself as disabled - I'm in a wheelchair, big deal. The chair's my legs, I save a hell of a lot of money on shoe leather, I just don't see myself as disabled.

Here, Jane acknowledges not only that as a child she used to want to be non-disabled, but that the very idea of walking was something that she did not understand. She had had no experiences of what it would be to walk unaided, how it would feel to be nondisabled. Indeed, in the children's home that she grew up in, to be disabled was to be normal. As a child her self-identity is, according to this account, therefore not about a reconstruction of normality through the creation of an autobiography that accounts for and explains her own difference from others, but through an autobiography based on others difference from her. She is not trying to account for loss, illness or physical decay in her self, but to seek how it is that others can do what she cannot. Her experience as a disabled child among other disabled children is not unique. It is the difference of others from outside the home that forces her to confront her self. This confrontation initially set up a sense of loss of self-identity, and she became fixated on the difference and discovered what it was

that she lacked. However, as her life developed the difference between herself and nondisabled people became normalised, there is nothing unusual for her to be a disabled woman. It is an unremarkable part of her sense of self, one so unremarkable that she does not incorporate it into her self-identity. As she puts it 'It's only bits of my body that don't work' and this has become habitual but unimportant, part of her ontological self.

This analysis of what it is to have an impairment was not only confined to people born with an impairment. For example Drew argued:

I had a view of my body before I had my accident and I have a view of my body now. I have a view that people have bodies. I know it is possible to change the body one has and the more money one has the easier that occurs. It's never been something that I have ever wanted to do. I don't , I've never believed as far as I can remember that it's really been important enough to me in that sense. I just think bodies are. I probably still in my minds eye imagine that I'm 16 and the schoolboy athlete that I was. That's how my deep down personally I feel about myself. Not a nearly 40 year old, middle aged, slightly overweight man. I know , I'm not dismissing the fact that I'm a disabled person I know that my bodies a different shape than it was before I can see that there's no muscle there any more I'm not pretending that there hasn't been change. If change is the right word. For example change happens all the time in any case and for all I know I could wake up tomorrow and discover that all this research into spinal injury has produced a cure and will take me back 10 years, but of course it won't take me back 10 years. It will take me forward to wherever I go. I'm not spending time wanting that to

happen or waiting for that to happen. I'm quite confident about myself as a human being here.

Impairment is not dismissed; indeed it is recognised. He is physically different from what he sees others to be and from what he feels his body should be. However, this difference is not internalised. He still, to a certain extent, feels that he is, and has the body of, the 16 year old that had the accident. This is not to suggest that he does not recognise or accept difference in his behaviour, or his abilities or the way that his impairment impacts on these abilities. For example he argued:

Last week I got in my van ready to go somewhere and discovered I'd forgotten my wallet. That just makes me so bananas because it is such a tiny little thing and I know it's going to take me ages because I transferred in, got everything together, locked up the house, got into the van which usually I leave parked out on the green, transferred from my wheel chair and I was just about to drive off and I thought I forgot my wallet and that adds, leaving my wallet in the house, puts probably 20 minutes to half an hour on to my journey and that's just so frustrating because it is such a simple little thing that anyone else would say I forgot my wallet, take two minutes. I've to transfer, fiddle with my keys, get back up that hill which is just outwith my capabilities. It's something that annoys me intensely when it happens. It just means a lot of the time I've to get more thoughtful about what I'm doing.

These accounts mirror those given on the body by some of the informants. This is as would be expected given that the self and identity are, of course, always embodied.

Giddens (1991) argues that 'Most people are absorbed in their bodies, and feel themselves to be a unified body and self' (p59), and following Lang proposes that unless this is maintained, the self becomes a false self. Dissociation results in a dislocation of the self and the creation of an unembodied self, 'in which the body appears as an object or instrument manipulated by the self from behind the scenes' (p59). The analysis of data presented here would suggest that the separation of self and body for disabled people is part of their biographical narrative, and echoes the findings of Cunningham-Burley and Milburn (1998) on people in their middle years. Giddens it seems, in writing as a white, middle-class, heterosexual non-disabled male, as one whose body is not used as a signifier of difference, fails to accept that for many, whose bodies are not universally accepted, part of the biographical narrative appears to be about constructing a self that allows a separation or reconstruction of bodily image and self-identity.

For some of the participants with degenerative conditions, the medical conditions that arose as a consequence of their impairment had also become a normal part of their lives. So Moira, a woman with MS says:

Well I suppose this sounds ridiculous. I feel I'm lucky, because as my MS slowly gets worse, because it's been so slow, I don't know it's happening. And then by the time I suddenly think, I could do this a year ago I can't do it now, I'm so used to it that it doesn't really bother me.

Whilst at first, for these informants, their impairment, in contrast to those born with an impairment, can cause a loss of the self, with time their corporeal knowledge, their knowledge of their usual body functioning, the spatial and temporal knowledge that is

founded upon this becomes altered and their current sense of bodily self is changed. Following Schultz and Luckman (1973;106) it could be argued that their body image has been altered and that these bodily images are variable. Being disabled is not a major part of bodily experience and consequently has little impact on the sense of self. Tommy argued that 'I don't wake up and look and my wheelchair and think 'Shit, I've got to spend another day in that', I just get up and get on with it'. This variability, however is also contingent and situated. It is embedded within the structures that they find themselves.

The Reconstruction of Normality in Constructions of Self-Identity

For others, self-identity as a 'normal' person is achieved not through a sidelining of impairment but through a restructuring of what is normality. For example Javid:

Well if I look at it, my disability and everything, when I look at it in my mirror (you might have seen this mirror is complete right up to the bottom - it is specifically for that, for me to look into it and see my legs, day-to-day life and how this leaning tower of Pisa is leaning on one side, that's what I am) I feel that I'm looking at myself and I'm thinking this big thing is going to fall one day, everything has to come to an end, so I'm going to fall one day, and I'm getting big, I'm not getting small, and I look like, not a monster or anything, I look like a normal person, apart from my body structure is different.

This normalisation goes beyond describing himself as normal. It is different to the examples above in that Javid directly challenges the social construction of what it is to be normal and what is a normal body. His self-identity is not premised on notions of roles or relationships, but on a reconstruction of normality. Like the informants described

above he perceives himself as both different and at the same time normal but he overcomes the paradox that this implies in that he sees himself as both similar to other people and as different, but importantly, this difference has little or no consequence. Self-identity is the product of a conscious action, and it is through this reflexivity that he exhibits his bodily agency. His is not a docile body, he does not meekly adopt a passive and prescribed notion of self identity, and he is not trying to distance himself from his impairment or the value systems that are attached to having such an impairment. The difference of his body is not bracketed, but embraced.

Keiron, talked about how, in the past he would have seen himself as a disabled person first

It's a difficult one to answer, I mean, the answer I used to give was a hundred percent I would have said disabled straight away because that's all I'd been taught. I'd say more a person who happens to have a disability in the same way, if you like that, I was reading about Jacky Stewart yesterday, now he's an individual who happened to have a talent for driving cars, he also happened to have dyslexia but it still didn't detract from what he was, and what he is as an individual. So I think first and foremost I'm Keiron Brown the person, and I know how to concentrate on that side more than I did maybe 8 to 10 years ago when I'd just came away from a lot of the negative things.

Later he talked about what it meant to be normal:

Well what's normal? You could have, say for example, tomorrow I could be able to walk with no hassle at all, but what about that guy in Japan, the sort of average

Joe who just decides, 'Oh I'm ok but I'll go into my bag and release this canister.'
This guy can walk about and is perceived as a normal individual. What's normality? You see some of the things that happen, and some of the behaviour of some folk, I mean what's normal. I think that's a word that people use but they don't really understand a lot of the time.

Here in a similar vein to Javid, Keiron questions the meaning of normality. In so doing he is not suggesting that by adopting a conceptualisation of difference and a challenge to normativity he can manufacture a self based on heterogeneity; far from it, Keiron does not see himself as different from other people.

The Political Consequences of the Rejection of Impairment as an Identifier

It could be argued that all of these views merely reproduce disablist practices. Through a denial of disability and impairment they are rejecting and distancing themselves from other disabled people (who ever these may be). By not self-identifying as disabled could be said to describe a state of self-alienation and inauthenticity. In the narratives of, for example, Keiron and Jane, the informants have moved in an almost exactly opposite way to that of gay and lesbian men, who strive to move from the closet in which their gay identity is repressed and to come out and claim a gay identity (Seidman 1998). This was as true for those who were active in the Disabled People's Movement as it was for those who were not. They tell a story of how, through their social experiences, they have moved from a position of difference, one in which their self-identity is dominated by social ascription, towards a position through which they resist this ascription and recover the self. The personal freedom that follows is not achieved through a demand for the recognition of difference, but through a wish to assimilate with the mainstream, to negate

a difference that is seen as demeaning. Bauman (1992) makes this point eloquently when he argues:

..the only content of 'identity' allowed in the shifting 'nows' is the *right to choose* an identity the right to renounce an unfashionable or otherwise unappetizing identity, to don a currently recommended one, to distinguish oneself (oneselves) not necessarily by being autonomous, but by having – and practising and above all demonstrating – the right to be autonomous, in case one wished to be. The agonising hopelessness of the struggle for self identity so moulded derives from the fact that victory is impossible; or, rather, that victory, if won, would bring more agony instead of succour. What would one do with freedom to choose identity at will, where the will is not authoritatively guided? How would one know that freedom has been truly won, if the choice of identity were not authoritatively preset and fixed. (Bauman 1992; 194)

For these informants being disabled is about living in a system in which people with an impairment are subordinated through relations that are contradictory to their own views of their self. This subordination is however challenged, they do not define themselves as other, they take choices and action despite this social constriction. These informants are creating an idea of themselves for themselves. They are not basing their ideas of self-identity on biomedical models that present disability as a tragedy. However, the construction is based, as Bauman (1992) argues, not on freedom or diversity, but under the guidance of cultural and bodily capital. Self-identifying as a disabled person it appears can challenge an individual's perception of themselves. The image of a disabled person as one who is weak and disempowered seems to be as potent an image to disabled

people themselves as it is to others who purvey this image, given that many of the informants chose to distance themselves from such an identity.

Self identity is not formed on the back of a call for difference. Being disabled, for many of these informants, is not about celebrating difference or diversity, pride in their identity is not formed through the individuals' labelling themselves as different, as disabled, but it is about defining disability in their own terms, under their own terms of reference. They are not, as Shakespeare (1993) argues 'subverting stigma, taking a negative appellation and converting it into a badge of pride ' (p253), but are reinforcing a stigmatised image of disability by denying that they are part of that. This has led writers such as Morris (1991), Corbin (1994) and Shakespeare (1996) to suggest that this struggle to attain 'normality' and eliminate the existence of impairment adds further to the oppression of disabled people. Morris has suggested that disabled people are, in effect, stigmatising themselves and whilst she does not go so far as to suggest that such people are suffering from what Marxists would term false consciousness, it is implied. She argues that such an approach arises because disabled people have little or no contact with other disabled people who could act as support and strength:

One of the most important features of our experience of prejudice is that we generally experience it as isolated individuals. Many of us spend most of our lives in the company of non-disabled people, whether in our families, with our friends, in the workplace and so on. Most of the people we have dealings with, including our most intimate relationships, are not like us. It is therefore very difficult for us to recognise and challenge the values and judgements that are applied to us and our lives. Our ideas about disability are generally formed by those who are not disabled. (Morris 1991;37)

However, it could equally be argued that they are not reinforcing oppression, but trying to make difference *not* matter. It is how this difference is not made to matter that forms the basis of the next chapter.

Some of the politically active informants, some of those who were recruited through organisations of disabled people, whilst rejecting an identity built on impairment, did identify with other disabled people when describing experiences of oppression. For example, Stella, in the following extract shows how such oppression forges a bond between herself and other disabled people.

If I am, if anyone is, denied access because of bad planning, bad design, through no fault of your own, inevitably you come away with - well, I come away with two things: I come away with a disappointment and a view of myself in one dimension as being lesser - in other words I have lesser access to certain things and therefore I must be a lesser person mustn't I? But the other thing that does for me because of the relationships I have, is to actually stimulate and challenge and say 'Let's change this'.....But what I would then do with that fact is to share it with other disabled people and do something about it.

In this way a common identity emerges, but this notion of a shared response was not common. This is discussed in more detail in the next chapter.

The Incorporation of Impairment into Constructions of Self-Identity

In contrast to these informants, there were however a small number of people, all women, who described themselves in negative terms. For example Caroline says:

I think that I look terrible, I actually just believe that... I think I'm just terrible. I just really wish I could... when I go to my bed at night, I think, I wish I could just fall asleep and never face another day. It's probably just a coward's way out, but I wish something would just happen naturally that I didn't have to face another day, you know? And then I wake up in the morning and it's another day to get used to.

or Eve who describes herself as ‘*a sad lonely character.*’ For these women, at first glance, the presence of an impairment seems to impact on their sense of self. However it could be argued that it is too simplistic to suggest that these two women describe themselves in such a manner because they have an impairment. Caroline talked freely about marital and other family problems, particularly concerning her daughter and Eve felt lonely and that all her friends had deserted her. She stated that ‘I’m feeling so isolated here, the only thing I can do is feel down.’

She felt embarrassed about her impairment and described how difficult it was to maintain relationships:

Well, you are so much trouble to people. It does take patience to deal with somebody who is in a wheelchair - to go out with them. You would have to have a car that they can get into to with a boot that is big enough to take a wheelchair and things

Like many of the informants, Eve talked about how difficult it is to go out with other people and how there is little spontaneity in her life because of the constant need to plan ahead. She described how, in contrast to the experiences of Moira above, her MS had recently led to a rapid deterioration

Eve: I would say the MS is very active. I am in a wheelchair, I can't walk and recently I have got very very shaky so that ... many things. I can't put my contact lenses in..... I am not feeling great. I haven't felt healthy for, well, the last few days - the MS has been very active.

NW; Does it come and go in phases?

Eve: No, everybody says that because MS can. I have never had remission not really, it has just been a gradual deterioration. Once it started, it has been getting worse. Over the last few months it has been getting worse quite rapidly.

Eve ascribed all her current problems as being the result of having MS. As she put it:

I just feel that before everything happened things were good and boyfriends were on the scene and marriage was on the scene and everything changed with MS.

After the first interview she moved to a new house that she now shares with another disabled women, and whilst she said that she felt slightly less lonely in her new home, she still felt down, and still felt that it was the MS that was the fault. She talked about a wish for a relationship and friends, for people that she could confide in. She was not sure

if life was any better and certainly did not feel any better about herself, although it was as she put it 'Too early to say'.

Caroline and Eve were the only two participants who, when faced with, for example an inaccessible building, tended to blame themselves rather than the architect or builder. Their sense of what Antonovsky (1978) calls coherence is skewed towards a notion of self that should be able to control and manage things beyond which they could, in reality, be expected to control. There are boundaries to our ability to control things, and if we fail to recognise these boundaries and attribute blame to the self for things that are the responsibility of others then self-identity becomes damaged.

Anne also talked about how difficult it was for her to come to terms with her impairment, and how this impacted on her image of herself. She talked about how she would like to be able to have an image of herself that did not incorporate impairment, but was unable to do so. She described how a friend of hers had, in trying to help her, merely reinforced the idea of difference:

Anne: You know, right, they look at you, right, this is the opposite, and 'oh, your disability's getting worse.' You know, you just want... you'd rather be asked what the weather was like today, but it's focused, so you end up hating your disability, and putting... and I do, I admit this, I put it under that carpet. People... well, if you know, going..... I tried to say... what was I going to say? I tried to say to her, 'Bernie could you see me without a disability_' But she could never see me without a disability.

NW: *She could never see you without a disability?*

Anne: *No. I asked her, cos I get really a bit fed up with people commenting on it all the time.*

NW: *What do you mean, she could never see you without a disability?*

Anne: *Em, like, she... [mutter]... because it's part of me, it's not something I could take away. That's what she meant.*

NW: *Right, so it's part...do you feel like that now?*

Anne: *Mmm... sometimes. Some days, I know it's there, right, but I don't need to be reminded of it.*

NW: *Right.*

Anne: *'Cos you know, constantly people are... it doesn't happen every day, but every so often, what happens is... Like, class a couple of weeks ago, was 'What happened to you?' You know? And I've heard people going to my... Lorraine was saying to my friend Frenchie, right, she was caught.. she didn't mean to be nasty, but she was saying about my disability again. You see, it comes up in different ways.*

NW: So you find that when people constantly refer to your disability it upsets you?

Anne: Yeah, it does, it does upset me. Possibly as well, cos maybe cos I've not accepted it, cos I've just went whoosh with, like, the Hoover.

NW: Yeah.

Anne: Uh huh. But it's a bit boring to hear it every time, you know?

Anne is being confronted by a friend, who, with the best intentions is trying to help her, but by focusing on her impairment is in effect inscribing difference, something that she does not want. She does not want to be different, like the other participants she wants to be the same, to assimilate and merge into the background, but her friend's actions appear to be running counter to this. In contrast to Archie above, Anne is not yet able to disregard these comments. She has not got the biographical history to be able to ignore these comments or to show others that her self-identity does not accord with their views of her and her sense of self. She lacks what may be termed 'reflexive power', an ability to create a self-identity and reject an identity fostered on her by others.

Conclusion

This chapter has presented data from the informants accounts about their own sense of identity, who it is that they think they are, and what are their images of themselves. It is clear, in many of these accounts, that the informants do not see themselves as disabled. That is, they do not claim an identity based on their impairment. To paraphrase Butler

(1990; 325), they reject a description of themselves as 'disabled people' in the terms articulated by those who write in disability studies. An identity as a disabled person, in disability studies, is created through a regulatory regime that, inadvertently, constructs a 'normal' body and in endorsing the existence of such an identity, disability studies perpetuates the notion of difference between disabled and non-disabled people, reinforcing the dichotomy. A notion of the normal body is, as discussed in chapter four, rejected by many of these informants. In this chapter it was shown how some of the informants rejected physicality as an essential, biological, determinant of the self. Just because they had an impairment, they did not perceive themselves as different to other, non-disabled people. For others, self-identity is not about difference, but it is about what they can do. Other informants questioned the whole notion of normality, challenging the social construction of what it is to be normal and what is a normal body, challenging the very discursive practices that are used to identify them. By questioning what normality is, they question the very basis that others use to describe them as different. There appears to be little support for an identity politics built on the notion of a common group identity of disabled people. The representation of disabled people as other is rejected. However, whilst Butler's theories are important here, in that they provide a theoretical basis for the rejection of a fixed identity as a 'disabled person' her analysis allows little room for agency. Identities, she contends are constructed through discourse, self-reflexivity is not recognised (Dunn 1998).

The analysis presented here supports the ideas suggested in chapter four on impairment, in that having an impairment becomes part of the everyday experience; it is normal for them to have an impairment. Having an impairment is, for them, a fact of life. It is, ontologically, unimportant. It has become part of their being, their ontological existence, and their identities are self-constructed in such a way so as to negate impairment as an

identifier. Awareness of the self is premised on a notion of what they feel themselves to be not what others suggest they should be. It is not the product of discursive practices. Even though this acts at an individual level, the agency exhibited in this action is a very political action, in that they reject identities others may wish to enforce on them. As the last chapter showed, these informants clearly live in a society which denigrates disabled people yet few of these informants have incorporated that into their sense of self and identity. This agency is in part, it seems, achieved through constructing a narrative identity that allows for a separation of body image and self-identity.

There were, however, a small number of informants, who incorporated impairment into their sense of identity. Identity impacted on their sense of self. However, as suggested in chapter four, this may be the result of other, interactional factors. All these informants talked about problems in their lives, and, as suggested earlier, it might well be that their other problems are focussed through their impairment. Indeed, given the discrimination that the informants felt throughout their day to day lives, as discussed in the last chapter, what is perhaps surprising, is not that there are some who describe themselves in the way that they do, but that there were so few. How is it that most of the informants were able to create an identity that rejected their impairment as significant, for whatever reason, in their identity formation? It is to the actual construction of their identity that this thesis now moves.

Chapter 7

Maintaining Identity

Introduction

The notions of self-identity described in the previous chapter are held despite, and in some cases because of, both the institutional discrimination experienced by disabled people as documented by Barnes (1991), and in face of the prejudice experienced on a daily basis, as documented earlier in chapter five. I was therefore interested in how many of these informants managed to maintain their self-definition in the face of these assaults. How was it that, despite these violations, they were able to make the body disappear and create and maintain an identity that was not built on difference. Conversely, I also wanted to look at how those who see themselves as different to, and lesser than, non-disabled people, construct their identities. In chapter five it was noted how many of the comments of nondisabled people were disregarded because they were seen as arising through ignorance. However, this does not explain how it was that these informants were able to ascribe ignorance to the comments of others, how they are able to write off these comments. The agency and reflexive processes employed by the informants are not uncovered.

This chapter explores informants' accounts that discuss how their self-identity is maintained through the attacks on it, how the informants were able, in most cases to create an autobiography that rejected, disregarded and displaced identities fostered on them and also how those who had negative images had arrived at such conclusions. It explores how the informants were able to come up with a notion of 'Who I am', building positive, or negative self images.

Experiencing Identity and Difference

Dunn (1998) makes a distinction between on the one hand cultural identity, which locates identity in a shared collective experience and on the other, a personal identity, one which is located in the material and social relations of individuals. He argues that while these two are obviously linked, in that personal identity is situated within an institutional and social relational context, and such relations are pervaded by cultural meaning, the process of separating out these two processes allows the identification of institutional structures, such as the family, work, friends, consumption and technological reproduction. So he writes:

Understanding how identity is constructed is therefore no longer solely the matter of the influence of history, culture, geography and power, but depends also on choices and constraints immediately available to individuals who as actors negotiate their lives within a broad field of social meanings and actions and within a range of institutional settings. (Dunn 1998;9)

This notion of a cultural identity as proposed by Dunn (1998) is similar to what Jenkins (1996;3-6) calls a social identity. Social identities, Jenkins argues, are a process; they arise as the outcome of negotiation and reflexivity. They are a social product, and emerge through interaction. Social identities are not fixed, they are in a constant state of flux and alteration. They are also plural and layered, we have not one, but many social identities. We live our lives in heterogeneous, diverse fields and a singular identity will not suffice (Rose 1993). Social identities come to the fore depending on the location and the action within that location. These multiple identities do not, however operate independently of each other, so Wenger writes:

Our various forms of participation delineate pieces of a puzzle we put together rather than sharp boundaries between disconnected parts of ourselves. An identity is thus more than a single trajectory; instead it should be viewed as a nexus of multimembership. As such, a nexus is not a unity, but neither is it simply fragmented. On the one hand we engage in different practices in each of the communities of practice in which we belong. We often behave rather differently in each of them, construct different aspects and gain different perspectives. On the other hand, considering a person as having multiple identities would miss all the subtle ways in which our various forms of participation, no matter how distinct can interact, influence each other and require co-ordination. (Wenger 1998;159)

As stated in the last chapter, in much conventional sociology, it is argued that identity is claimed through a notion of sameness, an idea that our identity arises as a result of our belonging to a particular group or grouping. We feel a bond with others, we feel solidarity with others when we feel ourselves part of a group and through this our identity is reinforced (Jenkins 1996). However, other theorists, for example Hall (1990) and Said (1979), whilst acknowledging a place for sameness, argue that our identities arise as a result of difference, fragmentation and multiplicity. In its most simple form, identity is the product of 'us and them', 'insider vs outsider'. Identity is the product of difference, the recognition of otherness. People define their identity against others. In this formulation, it is impossible to talk about a disabled person without discussing non-disabled people; we cannot describe what it is that makes a disabled person unique without discussing how they differ from non-disabled people. Yet, in the analysis presented in the last chapter it is clear that some of the informants reject difference and do not see themselves as different from non-disabled people. They do not identify with

other disabled people, and nor do they see themselves as different from non-disabled people. Whilst, physically they may be different from people without an impairment, this difference is not reproduced socially.

Disabled people are constructed as different and other by, in the Foucauldian sense, regimes of power/knowledge, what Butler (1990), among others, terms discursive practices. Davis (1995), for example, shows how statisticians in the late 19th century described and formulated much of what is now used to define a disabled person, a process that the geneticists employed on the Human Genome Project are now replicating. As Foucault (1984) argues, such technologies impose a norm, and all members of society are judged against that norm, difference is created, and society becomes divided. Further, not only were, and are, health professionals, statisticians, educationalists, psychologists and sociologists able to construct disabled people as other, they are able to do so in such a way as to try to make disabled people see and experience themselves as other, as different. Yet Foucault's theorisation of power, whilst providing an understanding of the way that power is constituted within institutions, and how that power circulates throughout society, is vague. As Dunn (1998;37) points out, there is little attention paid to the structural relations and material foundations of power. It is hard to apply his concept of power in the lives of individuals¹. At a personal level, as the last chapter showed, many of these informants rejected identities based on these norms and it is difficult to incorporate such views within Foucauldian theory.

The way that some of the informants described themselves is what Corbin would term a 'false self', one adopted by disabled people to 'preserve conformity and to fit in'

(1994;346). She argues for the adoption of what she terms 'an actual' identity, one premised on the proud label of a disabled person. What she fails to address is that for some of these informants the self-identity that they have chosen is the result of autonomy; they are acting as autonomous subjects, and to write off their subjectivity would be to further add to their oppression. There needs to be a recognition that human freedom does exist and that such freedom can be progressive. What is needed, as Fraser (1989) has argued with regard to feminism, is an analysis that is grounded in the notion of an autonomous subject. It is this that forms the basis of this chapter as it explores how, and why, the informants have claimed the identity that they do. The next section explores the process of identification.

Identity/Identification

The processual nature of identity has been theorised by Lacleau (1994) through the psychoanalytical concept of identification. He draws a distinction between identity and identification. Identity, it is argued, is an object of discovery or recognition (p2), whereas identification is a process of construction. Identification, however, arises through a lack at the root of identity, 'one needs to identify with something because there is an originary and insurmountable lack of identity' (p3). Fuss (1995) goes on to argue that identity emerges through identification:

Identification is the psychical mechanism that produces self-recognition. Identification inhabits, organises and substantiates identity. It operates as a mark of self-difference, opening the space for the self to relate to the self as a self, a self that is perpetually other. (1995;2)

¹ In Foucault's later work, especially his interviews, the notion of autonomy is made much more explicit. For example in the essay 'What is enlightenment?' (1986) he argues that subjects have the ability to choose

She argues that the process of identification results in both the generation of a sense of identity and calls that identity into question. Identity is constituted through difference and also problematised by difference. This mirrors the arguments of Laclau (1994) and Laclau and Zac (1994) in relation to political identity. What these authors are arguing is that through positioning identity as an outcome of a situationally contingent process of identification a clearer understanding of identity will emerge. It allows identity to be seen not as a stable entity, but as part of a continuous process of redefinition of the self (Mellucci 1996;51). Fuss (1995), by drawing on the work of Franz Fannon (1986), makes the important point that identification is a political operation, 'that the political is located within the psychical as a powerful shaping force' (p165).

However, whilst the ideas of Laclau, Fuss and other psychoanalytical theorists are interesting, what they actually provide is a platonic concept of how identity is operationalised. They provide, at best, a concept of identification that is grounded in theory and operates at an individualised level. It is difficult to apply such theory to empirical data, indeed it could be argued that the very fact that the Freudian notions of identification and identity formation operate at the level of the sub-conscious the interview methods employed in this study would make any attempt to work within such theoretical frameworks impossible².

In interactionist theory, the human subject is the best guide to uncovering the world that he or she inhabits (Plummer 1991). Through an analysis of the practical consequences of

a course of action, but his focus is still centred on threats to autonomy.

² Craib (1999) makes the point that psychotherapy involves, among other things, helping people to understand aspects of their personality of which they are unaware, and this is clearly beyond the scope of this research method.

actions, through an examination of the relationships and an exploration of the patterns of social life a 'real'³ social world can be uncovered. Identifications and identities emerge in the world of human activities, not disembedded philosophical speculation (Plummer 1995). Identity and difference are products of social processes. These processes include both socially and culturally constructed systems of inequality, as described above, but also, importantly, the ability of individuals to shape the self. As Dunn writes:

...the power of others to define is limited by the potentially disruptive possibilities of social interaction as initiated or forced by reflexive and rebellious selves. (1998;42)

The symbolic interactionist tradition stresses the way in which each person's self is formed by a reflexive process. In this process, our perception of how others see us plays a paramount part. It is to how the informants shaped their self that this chapter now turns.

Constructions of identity; identification as a disabled/nondisabled person

As the previous chapter showed, many of the informants do not self-identify as a disabled person. However, as the chapter on the body clearly demonstrated, the informants were well aware of their impairments. Their body is not 'black boxed', and this together with the daily rituals of abuse that they have to endure would suggest that they are well aware of their physicality. They are aware of what many people think of them and as Sheldrick (1997) so clearly shows, the forms that disabled people have to fill in to claim benefits such as Disability Living Allowance clearly articulate to them what the state sees as their

³ Reality, as Plummer (1991) argues, is a hypothesis and this concept should not be equated with positivism.

own bodily inadequacies. They are therefore conscious not only of the fact that they have a disability, but also of the way that society feels about people with impairments. It is therefore understandable that when they come to construct a self-identity they do not want to incorporate such negative attributes into that identity. However, as Goffman (1969) argues, they can only do this if they can persuade others to also accept that identity on these terms, or persuade themselves that others have accepted their own definition of themselves.

I was interested in how they managed their identities, what Plummer (1995) describes as finding themselves, the stories, the scripts that they work from. How they produce programmes about their own lives, to, as Giddens (1991) puts it, keep the narrative going and reflexively create and manage their own sense of self. How they turn themselves into social objects and what the object is that they construct.

For many of the informants identity was maintained through the image that they presented to others. For example Stewart described how he always dressed smartly:

I'm tidy and smart. I dress to impress, I dress because I like dressing, I like clothes ... I always have a suit ... I think appearance is very very important when I'm going to meetings and sit round a table with professionals. A sweater will not do for me, I'm competing with others and I will be as smart as them because that is the way I've always been ... sometimes I do feel I can be tactless in a way in the sense that I am determined to ... determined to make those around me... I feel that when I go to things, other people are quite smart casually ... shouldn't feel that they are kind of superior in any way. I'm not saying I feel superior, but maybe I

do feel superior because I have taken that trouble, but it is not everybody that wants to go out looking as ponced-up as I do.

Later he stated:

It might be that I'm compensating for my weaker problems; facially, physically that I can dress a bit smarter and detract from things. There have been many occasions when [my partner] has verified that ... when I'm in my suit people talk to me. We have had to go to odd things, a doctor or whatever, they are not fully taking into account the problems I've got, the physical problems. A lot of people don't ...for that sort of thing because I am creating this image like a bookcover. I think I look tidy and smart, the tie is dead right and I sit in a way - constantly occupy my mind with 'Am I sitting correctly?' 'Am I ...' I am trying to look ... not sliding down with a double chin or whatever. Extremely vain, extremely aware of it, and it does succeed sometimes.

Here Stewart described how, through dressing smartly and through controlling and holding his body in a certain way, people no longer treat him as a non person, but as an equal. He is therefore able, through altering the way others see him, to challenge discrediting ideas about his identity that others may have. People treat him with respect and listen to what he has to say. He has forged a new identity and this identity is built around an image of himself as powerful and capable. His identity is not imposed, stigmatising, from without. Adopting certain bodily styles and dressing smartly suffices, he feels, in constructing his identity in what Goffman (1972;189) terms anonymous relationships. In these encounters individuals know each other solely on the basis of an instantly perceived social identity and, this, should the relationship develop,

has an impact on future, mutual dealings. Stewart went on to express his anger at the way that he sees many disabled people dress:

I absolutely detest going to meetings where I see people who have been dependent on help coming out of sometimes hostels ... all dishevelled, sweaters all twisted round, and they have come to expect that is all they are going to get.

He talked about how it was no wonder that such people got treated as second class citizens and he told me how he had persuaded a disabled friend of his to adopt a similar dress code to his own. Dress is for Stewart, a prop, it helps him build up an image of who he is, and to project that image to others; it is an instrumental use of goods as representation of the self, one that is both effective and productive in his terms. Through social interaction and self-reflexivity, Stewart presents himself as the same, as not different from other non-disabled people. He forces others to see him as a capable agent and to see him and not his impairment. Through presentation of the self he is able to claim a mainstream identity and distance himself from an identity premised on the notion that he is disabled. He also recognises that this can produce problems, for example his comments above that when he meets doctors they miss his physical problems. He talked about how he could create an image that was so strong that he felt that at times people would think ‘*What’s he at because he looks OK to me?*’, especially when he was dealing with people from the social services about allowances or personal support.

The question that Stewart raises is what does he see his image as representing. It is not who is he trying to represent, but what? For him it represents someone who has a highly valued lifestyle, a powerful person, an image of the good life or happiness. Conversely, people who appear dishevelled represent the weak. It could be argued that in taking such

an approach Stewart is not resisting disabling practices, but accepts them and through his behaviour reinforces them. Yet his practices can also be read as mode of subversion rather than mode of compliance with mainstream representation. In the same way that Grosz (1994) argues that men and women are both equally caught up in modes of self production and observation, so are disabled and non-disabled people. Disabling imagery does not serve to make disabled people the objects of disciplinary control while non-disabled people remain outside of this control. We are all to some degree caught up in these power relations and no one is free of constraint.

Marion described to me how, when planning her new kitchen, she was determined not to have too many adaptations and so preserve her status as 'normal':

They [the occupational therapist] wants to make the kitchen with curtains in front of the sink so that you can go underneath the sink so you can go under there. But not everybody wants curtains. People want their house to be normal, for you to walk in, you being an able-bodied person, to walk in and your house to be normal. You wouldn't have a curtain on the front of your sink, would you? No.

Indeed I was struck by how few adaptations many of the informants had in their homes. In many of the houses, the only alterations visible was the presence of a ramp at the door and minor adaptations in the bathroom. For example Mark said *'The only thing I have is a monkey pull in the bathroom, that's it.'*⁴ It was almost as if what are described as Aids to Daily Living (ADL) served as identifiers to something that the informants felt that they were not. As Tommy said when I asked why he had so few adaptations:

⁴ He did however point out that, in his case, if he had too many adaptations in the home his partner, who is non-disabled, would find it difficult to live in the house

I don't want to live in a museum to disability

There almost seemed to be a sense of pride in the fact that they used or had so few adaptations to their homes. That their absence signified normality. This is similar to the comments in the last chapter by some of the informants with regard to the insignificance of their wheelchairs in the construction of their identity. They are attempting not to be defined by their impairments or their Aids to Daily Living but by what they see themselves to be. It amounts to a rejection of their imputed social identity.

The Struggle for Identity

In the accounts it became clear that these strategies were achieved through struggle. They were active modes of resistance and required energy to keep the narrative and performance going in the face of the daily experiences of oppression. Many of the informants talked about how they had to be resilient, for example Keiron told me when I asked him what it was that kept him going and made him want to live in the mainstream despite all the knocks that he got:

Well I think in a way it's because I'm a stubborn sod and I think maybe because I saw what the assumption was, what I could do and could not do and I felt well I'm not going to have this, I don't want that particular route. I didn't want to go down that particular avenue and I wanted to do something that was more constructive and because I feel that you can either say to yourself I'm going to believe what is being said to me, I could do the living in [an institution], I could do that if I wanted to but what drives me not to is first of all that I'm determined that I don't want that to happen, I feel I've got some sort of ambition and some

sort of pride and because of that, because I've skills that maybe some of the people in the [institution] don't have, maybe they've skills in other areas but the real tragedy is that they're never really probed enough, you know, but because I can do things, well I'm not going to let the skills I have got get stagnant, I'm not going to say well this is all I can do, isn't it great that I can put some stickers on some boxes or weave a basket type of thing. I'm not denigrating them, I'm not saying that that's crap, I am saying that would drive me out of my mind because I have got my own thoughts and my own ambitions and because of that I want to be me.

Keiron is arguing that his identity, who he is, is not how others see him, but how he sees himself, and that he is and should be seen as an active member of society, one who has skills to contribute. Importantly, he sees himself as different from other disabled people who live in institutions. He clearly does not identify with these 'other disabled people' and creates a distance between them and himself. In so doing he is able to claim an identity as one of the majority not the minority. Of equal importance however, is his recognition that it is not these other people's faults that they are in the position that they are in, but that they are there as a result of societal pressures, as does Stewart above. He later talked about the disability movement and how he felt no attachment to it or its demands:

Last week, for example, at my work, they had a group in from I think it was the Midlothian Coalition for Integrated Living, because we hire out the hall, and one of the people was talking to me, and I said of the 20 things I get worked up about, disability's probably about 25! And the lady looked slightly surprised when I said that, because quite honestly I think the way I get through things, you've got to

learn that there's other things to concentrate on, and other things to put your energy towards. I've seen people who get very angry and very irate and it doesn't mean that sometime I don't feel that way, but it's a different way of putting it across. Because I think sometimes when you get so angry that you lose your ability to relate to people, they think, 'Oh god, here he comes again, what's he going to say now, <snore>' and, you know, I don't want that to happen to me, because I think I've got other things to offer.

Keiron's struggle, like many of the other informants, is a personal struggle, not one built out of a sense of showing the world what disabled people can do, but what he can do. Similarly, Deirdre told me how for her much of her life was built around the idea that '*I want to prove people wrong....I want people to listen to me*'. Again, she did not identify as a disabled person, was not active in the Disabled People's Movement, and for her the struggle was an individual one. Joyce was also similarly motivated. She talked about how it is the very adversity that she faces, other people's attempts to discredit her that keep her going:

Joyce: I feel that if I was just sitting doing nothing it would maybe give them a chance to say I was lazy but it is the fact they are keeping me going like, not because if I did nothing for myself I'd just completely get depressed, I reckon and sort of give me a sense of achievement and a sense to keep going so I didn't stiffen up. I just wouldn't like to live like that. I'm lucky, I've had the choice to do that, some people haven't been able to do that and I feel very sorry for these people that could still be trapped.....It's just my attitude to myself.

NW: What do you mean your attitude to yourself.

Joyce: Like, I push myself more than maybe some people would do. Like I set myself goals and set myself, I want to set this goal, what can I do to try and achieve this and then think about it for about half an hour and then write a list of contacts and when I've got things clearly in my mind I just go for them, like I'm always setting myself goals. Like, the important thing's to go out when you can and just meet as many people as possible...[]...just that if a disabled person wants to do something, or any person wants to do something whether they are disabled or not, just go for it. Try not to let people stop you because they know what is in their minds.

Others took a more collective, group based approach to their identification and their struggle for recognition. For example Bob, who first of all told me how much his life had changed on leaving an institution:

I was let loose. I was able to go out and work, I wasn't under the hospital chains, I wasn't under the family's, I wouldn't say their thumb but, I went out and worked. I got my own very first job and that to me was independence, going out there and asking somebody for a job. Ok, I'm not saying that my employer's didn't think of me as disabled because they did, but they never actually let me see, or never treated me as a disabled person. I suppose in the early 60s that was something strange.

Not only was this important for his own sense of identity, it was something that he wanted other disabled people to experience. It was as a result of this that he became involved in the Disabled People's Movement

I am determined to change, in my small way, change society so that they can live happily, each of us, and not worry about each other's disability and put everybody equally. Not 'Oh poor wee crip, if I had a shilling I'd put it in your back' . I love a challenge.

Drew was more self-effacing. After describing one of his main drives as 'striving for equality' , he went on to argue that:

I don't have any particular desire to help save people, I don't have any particular desire to help others, as a student that was what I did and I think it was because I believed you lived your life and you gave to others the choices given to you and from my point of view you can either make morally superior choices or inferior choices and I try to make morally superior choices in my life; that's because I'm a morally superior fart basically.

However, whilst both these informants clearly identify with the disabled people's movement, they also reject the social identity ascribed to disabled people. Their project is to change not just the way that they themselves are viewed but the way that society views disabled people as a whole.

All these informants are clearly challenging their social identity. They recognise that they have an impairment yet through reflexivity, through personal experience, they challenge identities that come to them from the social world. Many of the informants talked about how influential their family and upbringing had been in helping them reach this position.

For example Collette told me how her father had insisted that she go to a 'normal' school, that she was treated just like her sister and that she was 'normal'. Similarly Marion said:

When I'm around family and that, they don't see the wheelchair, family and friends, an awful lot of them don't see the wheelchair, they just see you, and they expect you to be able to do things the way they do it, they don't think that, 'oh, it takes you double the time to do a thing,' or, you can still do it but it'll take you double the time to do it, they think you should be able to do it the same as them.

However, as many of the informants said, this construction of identity was not something that was easy, for some it took time. The accounts that the informants gave were aware of thoughts and acts in relation to the past, the present and the future; through doing and through experience many of the informants were able to produce new narratives and new identities. For example Sheila described in detail about how, in her past she had been unable to accept her disability, when she said:

I didn't like the fact that I had it, I hid it as best I could, like in the car, when you're sitting down....Certain things you look stupid doing, like at a disco, I would sit down because there was no way I was going to dance with crutches just some things like that.

She then went on to about how, as she had grown older she had become more comfortable as a disabled person:

I was at a wedding, and I thought, my walking isn't good, but I can dance holding on to people, but I don't feel in control, not as confident as when I've got my

crutches, so I thought 'Bugger it, I'm goin' to do it', and got up on the dance floor with my crutches and I was up for a while and they couldn't get me of the dance floor. So I think certainly, I don't like having a disability, it's not easy to accept when you're younger, it's easier to hide.....I think I accept it better now, there's not a lot I can do about it, I'm getting more mature. I accept it because I think again, I don't feel in myself that it can stop me doing anything

For Sheila, then, identity emerges through action, through an ability to do whatever she wants. Identities exist in time, they are the product of a reflexive process. The phenomenal experience of impairment is not about what you cannot do, it is about what you can do, and through doing what it is that you want to do an identity emerges that is not constrained by what society decides disabled people are, but by what the individual decides they are. These are what Somers and Gibson (1994) term ontological narratives, in that they 'make identity and the self something that one becomes' (p 61).

Some of the informants went so far as to criticise other disabled people who choose to campaign for disability rights, because, as they saw it, their campaigning methods further reinforced the idea of disabled people as helpless:

Programmes that I've watched, they're all making out that disabled people they've got in these programmes can't really look after themselves, they won't go out to help themselves, and they won't ask this or do this, you ken what I mean. For example there was a thing on about a month ago, and it was about the guy who tried to get from his house, in Central London, to the employment office and it took them almost a day. The guy was going to, like, the train station before he found out that the station had steps - you wouldn't do things like that, you'd phone

up, you would look ahead, plan in advance, I wasn't too happy about that, I wasn't a hundred percent with that programme. He was probably the same as me, maybe, T4/5 and they made him out like he was a tetraplegic or not meaning offence to tetraplegics in any way but they made out that the guy was more disabled than he was, that's what came over to me. And I've noticed that about 2 or 3 programmes on the telly.

They are determining their own identity through a presentation of the self and through action rather than having that identity determined for them in that they choose what it is that they wish to identify with. They do not identify with what they perceive to be the normative views that society hold about disabled people. This is a risky and at times difficult strategy, for they leave themselves open to the risk of being discredited, of having their identity challenged and having an alternative identity imposed on them. The anxiety and uncertainty of this strategy is exemplified by the language used by some of the informants about how they negotiate their way through social interactions. For example Stewart describes himself as 'arrogant', Sheila as 'forceful', Wilber as 'thick-skinned', Keiron as 'stubborn' and Collette as 'independent and a bit tough'. She went on to describe how 'I sort of developed a shell to just to protect myself and it is very hard to go away sometimes so I can be quite brash and harsh. A lot of my friends have pointed out that I am quite unladylike.' As de Swaan (1990;1) has pointed out 'maintaining normality is hard work'.

Reducing the Struggle and Affirming Identity

This anxiety is, however, reduced through a number of different ways. Firstly, as described in chapter five, informants discredit those who attempt to discredit them by writing off their comments as the product of ignorance. Secondly, as documented earlier

in this chapter, through the image they present to others. Thirdly, they build up a group of loyal, supportive friends. For example Stewart said:

I am extremely lucky to have friends and they are not friends that are sympathetic, if you know what I mean. I have no time for sympathy. I have no time for friends who 'Oh I'll be friends with Stewart because he's got a disability' ... but the friends I've got are people who have known me with a disability, but not one that was a major problem in life .have done all the things like staying with friends, driving all over for the best part of my life, and hell-raising too.

These friendships provide affirmation of who they are, as Stewart makes clear, When I asked what were the most important things in their lives, family friends and relationships were cited, among other things⁵, by almost all the informants. For example Deirdre said:

Bill [her partner]. Just knowing that people care about me as well. Even if they don't, even at the time I don't think that they do, knowing they're there, just going out, having friends to go out with, just being able to say my point and people to listen, People to talk to.

⁵ These included owning a car, having a job, and their homes, all items which enable them to live within the mainstream of life. For example, without a car those with mobility impairments are restricted in their ability to move beyond their immediate neighbourhood. Many of the informants who worked pointed out that they didn't need to work for financial reasons, that they would probably be as well off on benefits, but that they worked for something to do, as way of meeting people and to get out of the house, to give a reason to their lives. One or two were also highly critical of disabled people who choose to live of benefits and felt that it was too easy to get benefits and that these people gave disabled people a bad name.

When I asked Stella at the end of the second interview about how she felt that they had gone, she said that she was surprised by the emphasis that she had placed on relationships throughout the interview.

I think I am very conscious, I am aware throughout this whole interview, that relationships play a key part. I might not have predicted that, but it does make sense

What appears to be happening here is that the informants use friends, family and close relationships as a means of reaffirming their identity, how it is that they view themselves. They set up a loyal supporting group and it is through their interactions with these people, people that they can trust and people who think like them, that they derive their identity. Self and identity are created through social interactions and through the views of others, but the views to which credence are given are tightly controlled. They only ascribe importance to the views of a limited number of people. Not only does the use of same thinkers serve to confirm their view of the self, so to does the fact that people are open to change, are willing to have their stereotypes challenged. As Archie put it:

I've actually spoken to some.... this girl once, right, my wife's cousin's wife and we were at this party and she was sitting across the room and never spoke to me and my wife went upstairs and she came across and we were talking away and 10 minutes later she said 'Archie, I wish I'd talked to you earlier' and I said 'How,' she said 'I was feared to talk to you.' I said 'You shouldn't be scared, I am just a normal person,' she goes, 'I see that now.' You know the attitude ,you know what they are thinking about the chair, they think 'Poor man he's in a wheel chair and he can't do this, etc.' I tell them straight what I can do, what I am like. I say 'If

you are in a wheel chair, if you are able bodied you can be a total bastard, and a total bastard in a chair,' It depends on your - I explained how I feel about life. And once they understand I am just a regular guy to them like anybody else then the chair aspect goes away, it is just a one to one sort of thing. Everyone is curious about anybody, you see a black person, a disabled person, whatever, they are always curious, they are scared to offend, it is actually breaking the barriers.

The fact that people are willing to be taught, that through social interaction common social prejudice can be overturned, seems to almost make these informants 'missionaries' for their point of view. They set up, control and police their own 'webs of interlocation'. Within these webs they are able to make demands on how other people perceive them, how they are treated, and can claim an identity of their own making. This also goes some way towards explaining why so many of the participants used the word 'ignorance' in relation to other people's views on disabled people. However, as the next section shows, their identities were always open to challenge.

Challenges to Identity

Claiming an identity built on sameness is not a simple process. As the section on the struggle to maintain an identity showed, strategies have to be developed to meet challenges. Identity is open to challenge by people who are not part of the informant's immediate social network, it can also be challenged from within their network, or from people who come into that network. For example, Sheila described how, whilst her friends may have ceased to comment on her impairment, others who were new to her social network continued to do so:

If you are out, like I do, like going out with my work mates on a Thursday night say, or something like that, you're maybe meeting new people, friends of friends, or things like that, people are usually OK. You're sitting down and having a chat and then you get up to go to the toilet you pick up the crutches which haven't been seen until that time, 'Oh what happened to you.' It becomes a big issue. What do I say? Do I make too much of it? Do I let it upset me? Maybe it is me, but it can spoil a night. I just think people aren't educated enough about people with disabilities, especially because there is not information.

Here again, the problem is seen as not one of direct prejudice, but of lack of knowledge by the perpetrators.

It can also be challenged by structures beyond the control of the informants and their network. For example, many of the informants talked about how they often felt that their non-disabled friends excluded them from some social gatherings because of access issues, that they were going to go to a venue that they knew to be inaccessible and that they couldn't include them in the planned activity. They also described how, because of access and transport problems, they were unable to do many things spontaneously,. If they were planning to visit a new area or a new pub for example, they would have to phone in advance.

Others pointed out how being disabled could challenge friendships. For example Mark said:

Mark: I had one particular very good friend who I used to go out with every Friday night. He started to go around with another guy who I knew but didn't

know that well, but they would never invite me along because I think they used to go out in the hope that they were going to pick up girls or something and they used to look at me and think, if he comes with us, will he be a hindrance to us doing this. So they'd got the feeling that I was just going to be in the way and they'd be doing something that I wouldn't be a part of, but when we did go out together, I didn't feel excluded or anything.

NW: Did that bother you that they were excluding you from part of their life?

Mark: Yes, it did annoy me a lot. It got to the stage with this guy, together with other things unrelated, that I decided to end any friendship that we had because I felt like he was treating me differently.

His ex-friend has not treated him as the same, but as other, and has ascribed an identity to him that does not accord with his own view of himself. Mark has therefore ended this relationship. This was done not because his friend was a threat to his sense of self, but because he knew that his friend's view of his identity was wrong, and if his friend felt that way about him then he was not treating him as an equal.

Similarly Leslie talked about how, being disabled, meant that she felt unable to take part in a lot of the conversation and how this impacted on her relationships with others:

Leslie: You find with some friends, they don't talk really about sexual matters. Some will and I quite like that, I like ones that do just talk away about their sex lives, if that would have been in their nature anyway. I can't contribute, if there isn't one going on, I can't say I know what you mean and yes this is happening to

me right now. There might be friends who in the past would have talked about that side of life but who don't now. I've kind of lost touch with friends like that. You see it does change friendships too.

NW: In what way?

Well that's one prime example, my best friend out in [...] was from Glasgow and after the accident I think there was a lot of mixed emotions - she was able to go back to [...] and was having a great old time and I was obviously very jealous. Then she came back to Glasgow, went back to studying as a mature student and started to slag off the very course that I'd done, years ago. But that's all beside the point - the disability bit was, I'd been her buddy for going out and meeting people and all this, and now if she was doing things like that, she'd do it with other friends - I was kind of the wee dog that sat in the house and was good to come round to on the Thursday or whatever. And there was always a lack of invitation and enthusiasm about having me along. Not all the time, they masked it very well but it was always like if they wanted a really good night out I wouldn't be invited. The relationship, talking of relationships and things, did kind of stop. I mean you do think to yourself, how the hell would I ever manage in a relationship, from a sex point of view, and the only little experience I have had taught me that the fact that the person was disabled, he got to know me very very slowly meant that things were alright and they just went very slowly. Any relationship would be a very slow process and the thought of, well I've had able-bodied people say to me, 'I feel the same about my legs,' but for them to see my bottom I would need to have a hundred percent trust and I'd just feel that this was a real, very close, you know, it would have to have come a long. The good thing

is that I think if I hadn't had the one experience I have had I might have been more bitter and thought that side of life is utterly impossible and could I ever ever, whereas having had that bit of experience I can see that it's not impossible and that never ever could let anybody see me - that might have been how I'd felt. But having had a right close relationship I can see that it's completely different from being able-bodied and out and about as a woman, being single. I'm sure that people who've become disabled who are in relationships, they're going to have a lot of problems too, I mean I was single, I can't speak for what it must be like if I'd been in a relationship although I've seen a lot work and I've seen a lot fail, because it changes everything.

In this example, Leslie, through her experiences, and through reflecting on those experiences, is able to downplay the importance of the views of her friend and, whilst recognising the change that acquiring an impairment has made to her life, still feels, as she puts it, 'very positive about myself'. As she reflects on her self, her identity is not the product of biological or environmental constraints, but is the result of an autonomous definition of the self. What all of these accounts show is a capacity to shape and change everyday relationships and in so doing assert autonomy and a right to name the self. Leslie, for example refuses to identify with an idea that being a disabled person is a tragedy. She went on to say:

I make an effort not to dwell on things that have the potential to make me quite depressed and my way of doing that is to focus on what can be done and I have to work that out myself. You've different theories of dealing with things that way. Some people might turn round and say you should work it out, talk it through but talking it through won't change it, it is a cut and dry story, I can't do it, the next

step is what can I do, how can I have an enjoyable holiday, how can I possibly approach that other way that maybe in the future I could have a holiday, or learn to drive again, possibly with a helper and go to France and tour about. No rather than sit there misery-laden because of what I can't do and really I know people cringe but there are people worse off, things could have been much worse.[...].There was a man in hospital across the way from me last year and he was telling me a story, he had been in a wheel chair for 24 years and he looked very unwell, his level of injury didn't limit him much at all and he'd talked about the early days when he was 17 or 18 at the time and he was going through all the 'why me, why me, not fair,' and he wasn't and isn't terribly religious but there happened to be a priest that he'd been talking to one day and the priest said, 'Well, let me ask you this, have you ever thought about it this way, why not me?' When you think, the way I interpret the misery, the diseases, the accidents and injury, the wars everything that is going on, my mum lost a very close friend through cancer, had it one minute, diagnosed one minute, dead the next, why not me. Why the hell should I be exempt from any suffering, why should I sail through life and not have anything nasty happen to me and why should my nasty thing be the worst thing that could ever happen to anyone in the whole world. So these are my, why not me, who am I to think I should be allowed to have everything right. And the other thing I feel strongly about is that there are worse off and I have been lucky, about a cm away from having no use in my hand and arms, I have been very lucky.

This notion of acceptance was something that came through in many of the interviews. For example, Tommy told me *'I just think you have to learn to live with it and get on with*

life.⁶ This is synonymous with Antonovsky's (1978) concept of comprehensibility within what he calls the Sense of Coherence. This is explored in the next section.

Acceptance and Identity

A lack of comprehensibility or lack of acceptance, was something that was apparent in the few interviewees who felt that they were different and that their lives had been ruined by their impairment. For example Caroline told me:

Caroline: I just don't accept it anyway. I tended, when I could walk, to do silly little things, Like Thursday night say, the milkman would come to the door and he blethered on and on for ages and my husband said 'Why didn't you explain you had to go now and sit down because it was sore standing there'. I said 'I can't, I just felt embarrassed' almost to tell. He'll be thinking 'oh I don't believe her' I thought I looked completely normal, I looked as though I had nothing wrong with me.

NW: Do you still feel embarrassed?

Caroline: I feel embarrassed if someone comes in who we have never seen before and there are both my daughter and myself in a wheel chair, you feel embarrassed then.

NW: Why?

⁶ This notion of acceptance however should be treated with care. Almost all the informants talked at one point or other about the problems that they faced because of their impairment, and were clear that having an

Caroline: Because you think they'll think it is something genetic.

NW: Why does that make it any better or any worse?

Caroline: It makes it worse in a way because they'll be thinking 'Oh imagining inflicting it on your daughter', to pass it on because I would think if someone had that and in a couple that through no fault of their own had a boy with muscular dystrophy and he maybe gets married and I don't know how it works and it goes all the way down the line, usually it affects boys with muscular dystrophy. I think they should take responsibility and not have any family.

She talked about how she felt that all her friends had abandoned her, she only saw them once every three months or so and always at her house, never in the town or at their house. They treated her differently. What is interesting here is the contrast between the quotes above where, for example Mark abandons people who do not agree with him, whilst Caroline feels that they have abandoned her. She also talked about how difficult she found it talking to other disabled people:

Caroline: When I first moved here to [a disabled housing complex], I had MS, it was diagnosed but I was walking about and it was then that I felt, oh I couldn't bring myself to know anyone disabled because there was here, actually staying, from a university or a college a few people staying in the guest room in the complex and they had - thalidomide, poor souls were here they had really badly thalidomide and I went out of my way not to speak, put it this way if I was near

impairment was not a good thing. Impairment is accepted, but not embraced.

them I would smile but I wouldn't go out of my way to think oh, go out and befriend them or talk to them, I feel ashamed of myself now.

NW: Why?

Caroline: Well, why didn't I do that, go out and speak to them because they seemed really happy and how could they be really happy, I don't know how they could be happy. So awful, it was really bad, I just didn't want to speak to them.

What was clear from her accounts, and those of Eve and Lucy, was a distancing between themselves and other disabled people, but not in the way that others distanced themselves from disabled people. Lucy, who was the only informant who refused to have a second interview, said to me when I 'phoned up to make an appointment for the second interview:

I don't really think that you should be speaking to me, I'm not like all the others that you're talking to. You see, I'm going to get better, I'm not going to be in this chair for the rest of my life, I'm not like them. I'm different, what I have to say isn't the same. What I have to say doesn't matter, 'cos I'm going to get better.

Eve also distanced herself from other disabled people when she said to me:

Eve: I think there is a lot of people who are physically disabled and there are quite a few people mentally not together. I am finding it difficult to be physically disabled and mentally ok

NW: What do you mean mentally not together.

Eve: I know quite a lot of people who are depressed or gah gah or whatever, there is quite a lot who can't have a conversation because I don't know, their disability is affecting their mind, who cannot have a conversation.

Here Eve equates physical disability with mental disability, not in herself, but in others, and in so doing separates herself out from other disabled people. It is not that she does not identify as disabled (see her comments in the last chapter), it is that she equates disability with tragedy. She talked about her new flatmate, and what 'a dreadful state' she was in. For her being disabled is a major problem; it is undignified, it pollutes her image of herself and she is unable to see beyond it. She talked to me not only about how difficult it was for her to talk about, but also about how her family, especially her father, refused to discuss it. She said that her whole family felt embarrassed by her, that she rarely went to, or was invited to, family gatherings. She had lost contact with most of her friends, and was unable to do many of the activities that she used to do:

I've always been working, I can't do that now. Always been very sporty, I can't do that now. I've always been very horsey, I can't do that now. I have always been into cooking, I can't do that now. There seems to have been a lot of things taken away from me.

I asked if she ever went to see any sports, or went to meet any of the people that she used to play sports with and she replied:

No.....Because I probably'd feel frustrated by not being able to do it and watching would be depressive.

For these women, being disabled is not about what they can do, it is about what they can't do, how different they are now compared to how they were before their impairment, and how, in their eyes, their impairment has prevented them from taking part fully in a social life. All three of these informants talked about how sad and depressed they were, how they rarely went out, and how little they felt that life had to offer them. Becoming disabled has, for them, been a tragedy, and they are for whatever reason unable to take a pro-active, elective approach to the construction of their own identity. Identification is not the result of challenging social ascription, but is passive. There is little attempt at defining an autonomous self. Their identity is based on a phenomenal difference built on a permanent boundary, ideologically defined by culture and turned into metaphysical fact. They are not able to 'give in' to their impairment, to do so would be to become embedded within something which they see as abject. Yet, at the same time, they see their life defined by difference, a difference that they feel powerless to overcome, a difference that is all embracing and cannot be escaped. They are not able to claim 'normality' because they can find no social justification for such a claim.

Melucci (1996;101) makes the point that through encounters with others we expose ourselves to difference and we are challenged to both recognise our own uniqueness, but also to seek a common point of contact. It is this latter action that these three women seem to be unable to do. The other informants, whilst recognising that they are always already different, present and identify with an identity that is similar to that of nondisabled people. This is based on an ability to perform. Through their bodies they

express themselves as 'normal', as the same as others. The case of Moira described below might go someway towards illustrating this.

Moira, at the time of the first interview, had recently moved into Edinburgh from a rural area where she rarely met or saw other disabled people. The first interview was a difficult experience for both of us. Almost all the questions that I asked her were, according to her, inappropriate. Her life was, she said, dominated by MS, and she wondered how I could even ask her if she thought that she was healthy. She only liked to think about herself in the past tense as 'me walking, me running' and she had great difficulty thinking about herself in a wheelchair. She talked about how different she felt to all the 'other poor souls' who lived in the housing complex that she lived in. She described how she spent most of her time reading about cures for MS, how she had tried diet, medication, alternative therapies, although she had recently turned down the offer of hyperbaric treatment because she felt that she could not face the possibility of another failure. She had very little that was positive to say about her life.

However, six months later her whole attitude had changed. She talked about how she was 'getting more and more confident in herself' and described how and why she felt like she used to feel:

I got it in my head that I was something unclean, that I didn't want people to see me in a wheelchair. And it's quite strange, I was down at physio and I was saying this to one of the young men there, I said I've met women here and they've said, 'You have so much confidence,' and I said, 'If they only knew that I keep creeping into my shell,' and you see there were very few people in wheelchairs[where she used to live], so really and truly, if you went in to town, people looked at you. So

I stopped going, I wouldn't go out.....[..] I honestly, I don't know, this friend, she is a social worker and she has worked with disabled people and in that respect I am one of the luckiest people because if I didn't know her, she comes with me on all the holidays. And an aunt from up north did meet her she said it is because of her I'm the way I am. I don't think it is, it is as if coming here I've seen what other disabled people can do and it's as if they can do it, so can I. And that just started me wanting to go on holidays and go out because there was no way I would have gone to a pub, I couldn't believe, different people would say 'Tonight we will go to the pub for a drink' and I thought but you're disabled, you're in wheelchairs, how can you go to a pub and I discovered here everybody can do anything they want to do and that was it. That started bringing me out a bit.

She talked about how, through meeting other disabled people, she felt able to take control of her life. She described how she had changed in herself:

It's as if for 25 years I've been dead and it's as if suddenly I'm coming alive again....I like myself.

She talked about how she used to be unable to think of herself and how she was 'I probably lived in a dreamworld then.' She used to feel 'As if I couldn't cope, life wasn't worth living.....now I've discovered that I can manage or cope with all sorts of things, I just think it has all given me confidence.'

She also described how she no longer even bothered to read the MS Society's newsletter and had stopped reading about MS. When I asked her why, she replied:

I suppose then I kept thinking I will read something that will be a cure and I suppose it finally hit me so far there isn't a cure, so. I just feel what is the point of reading through all this stuff.

This final comment sums up Moira's changed attitude to herself and her impairment:

I was a poor disabled lady, but now I've discovered I wasn't a poor disabled lady after all, I was somebody and I could go where I wanted to.

For Moira, identification as a person, as somebody who could do whatever it was that she wanted was achieved through seeing what it was that other disabled people could do and, importantly, rejecting an identity built on disability. Whilst this may be read as her adopting an identity based on the experiences of other disabled people and her identifying as disabled, it could be also be argued that it is not as simple as that. She has thrown off the limiting identity of the past and formed an identity which is forged around choices and an ability to make these choices. She has been able to identify with a life that she wishes to live and also who she wishes to be. The 'new' identity is one that is constructed by her and not for her and she directly challenges the idea of herself as a 'poor disabled lady'. Through meeting other disabled people, seeing that they were able to do 'normal' things, like going to the pub, working and so on she was able to breakdown an identity built on difference and inadequacy and replace it with one built on sameness with non-disabled people, on equality of opportunity. Her experience is different to that of Sheila above in that she drew from the experiences of other disabled people. As the next section shows, many of the informants did talk about shared experiences with other disabled people.

Issues of Commonality

Many of the other informants also talked about how much they had learnt from other disabled people, yet these relationships have not led to a construction of a common identity built around disability. Whilst many of the informants made it clear that they did not actively seek out disabled people as friends and that most of their friends were non-disabled they did talk about some form of common understanding with other disabled people, especially those with a similar impairment. For example Tommy:

NW: Are most of your friends able bodied?

Tommy: Yes, most of our friends, but I have the basketball and I have a lot of friends there, I have two or three close friends who are in wheelchairs but I used to have pals at school, most of my pals that I do have though are able bodied.

NW: Do you find there are things you can talk about to disabled people that you can't talk to able bodied people or vic a verse?

Tommy: A disabled person has gone through the same thing as you so they can relate to it whereas an able-bodied person..

NW: What sort of things?

Tommy: Well, health things, sexual things, whatever or just everyday things, you want go to a certain pub you can ask 'Are the toilets accessible', things like that. General day to day things, chit chat, if you try to talk to an able bodied person

they'll try to understand but they can never understand it, somebody else in the same situation who can understand it. It's like somebody who's coloured, they get racial abuse and they'll talk to you about it and you'll never understand it because you've never been there, in that position, so you can't appreciate what they are going through but you can understand it, but until you are in that position you'll never really understand it.

These relationships tended to be context specific, situated and to have grown out of specific impairment or disablement related topics. For example, Archie talked about the advice he had got from other paraplegics on help with sexual problems. Many talked about their friends in the housing complexes in which they lived. Keiron talked about his friends from his school days and Arnie talked about his friends from his sports association. If they had friendships with disabled people, it was more a result of circumstances. Indeed, in the example of Moira, above, it could be argued that she did not seek out other disabled people to identify with, but that her relationships with them grew as a result of her moving into a housing complex designed for disabled people. Only one of the informants, Stella, talked about specifically seeking out disabled people as friends.

Conclusion

Identities and the identification with a particular identity, are, for many of these informants, created through adversity. It is the social and physical barriers that have constructed a grid in which, for some of the informants, the struggle is not to identify oneself as a disabled person, but to identify oneself as an agent, as someone who is socially capable. This is achieved through the presentation of the self in such a way as to downplay difference, through disregarding prejudicial comments and through supportive

social networks. These constructions of identity around a concept of 'normality' are not and should not be read as attempts by the informants to pass as normal as described by Goffman (1963;42). They are not trying to hide their impairment, indeed the visual nature of their impairment would make such an attempt futile. Rather, this should be seen as a resistance to the inscription of an identity based on a stigma, they are trying to assert what they see as their personal identity over what they feel some others may identify them as. It is also quite clearly not a coping strategy, but is more a way of being. It is a rejection of the imposition of that name, the social essence of a disabled person, that forms this reaction. Their identity emerges through relationships and social experiences that serve to validate their own self-image, one of normality and sameness.

The ascription of 'disabled person' assigns an essence, a competence, or an obligation of being on that person. It signifies what he/she is and how he/she should conduct themselves. It imposes boundaries and signifies what someone's identity is and in so doing informs him or her what he or she must be (see Bourdieu 1992;120-121). It is this idea of what they 'must be' that many of these informants reject. Many of the participants do not see themselves as victims, either as tragic but brave victims of a weak body or victims of a society that excludes them. They are autonomous subjects who resist, and in so doing have rejected an identity built on domination. Their impairment does not limit them to any particular identity, they are free to claim to be whosoever they wish. As pointed out in the last chapter, there are cultural limits on identities and it could be argued that, as Morris (1991), among others, suggests, the cultural representation of disabled people precludes identifying as such. This argument, however, suggests an essentialist element exists for disabled people. By not identifying as disabled are these informants denying who they are? Or is it that by defining themselves they are rejecting

assumptions that others may have about them, as Collins (1990) argues in relation to Black women.

Many of these informants went to great lengths to prove that they are not different from non-disabled people. Identifying as a disabled person implies, for many, an identity that is posited on marginalisation and subordination. Whilst some of the informants may view other disabled people as such, it is not a position they claim for themselves. Their agency enables them to present themselves as mainstream and as active and able to challenge. They are not merely the subjects of power. They have capacity to act upon both themselves, for example, in the presentation of the self, and others, for example in proving that they are socially capable. The development of this capacity is not without cost or risk. They are constantly open to challenge as they strive to become other than how they are perceived. Their identity depends on intersubjective recognition and as this can often be denied they have to develop strategies to keep the narrative going. Nor, as both this chapter and the last chapter show, do they ascribe to a singular identity arising through either a shared experience of impairment or disablement, or cultural heritage. Consequently, there is no preoccupation with group membership, indeed they actively campaign to ensure that they do not belong in that group.

Those who constructed their identity through a notion of difference appear to embrace the cultural stereotype of what a disabled person is or should be. Disability is, for them, a tragedy. Impairment and disablement form a grid through which they have developed a mode of being and an embodied identity. They appear to have no access to self validation as the other informants in the study have and, consequently, accept the conventional idea of what a disabled person is.

The analysis of the data presented in last four chapters, whilst split into four themes, shows strong links. For example, those informants who described their life with an impairment in such a way as to suggest that the impairment had become taken-for-granted and its presence part of their habitus were also those who rejected an identity built on the presence of an impairment. Similarly, those who did not see their impairment as part of their embodied being were those who described themselves as different. Strategies employed by some of the informants when faced with oppressive practices were similar to those used by the informants as they struggled to maintain an identity built on sameness and rejecting difference. Impairment was, for many of the informants, made apparent through disablement. It is clear that if a social theory of disability is to be developed, then such a social theory must include all of these elements. Issues of identity, embodiment, self, agency and structure all have to be included. Living with an impairment in a disabling society produces a lifeworld in which all of these elements are experienced interconnectively and also dynamically and this lifeworld is both actively produced and, at the same time, constraining. It is the implications of this that the next chapter addresses as it discusses the inferences of this analysis for disability studies and for the disabled people's movement

Chapter 8

Impairment, Disablement and Identity

Introduction

This discussion brings together the important themes that have emerged from the analysis of the data, linking up the findings with previous writings on disability and the wider issue of disability politics. Developing this link is important for, as Barnes et al (2000; 219) point out, if disability research is to serve any purpose then it must contribute to the process of enabling disabled people to empower themselves. In chapters one and two it was argued that most research on disability from within medical sociology has tended to be based on normative assumptions. The presence of a chronic illness or impairment marks out disabled people as 'deviant' and these conditions result in restrictions of activity. Research that has emerged from the disability studies paradigm has, in the main, tended to downplay impairment and argues that the restrictions of activity experienced by disabled people lie not in their impairment, but in society. Further, disability studies bases its theorising on an unreflexive acceptance of the disabled/non-disabled distinction. For medical sociology, the focus is on the experience of living with an impairment whilst, for disability studies, emphasis is placed on disablism and material relations. This, as Thomas (1999) points out, has resulted in two different research paradigms, each researching different dimensions of the disability experience. This thesis has attempted to merge both these paradigms. It has explored the experiences of living with an impairment, but has located that experience within the wider socio-cultural environment to take account of disabling practices. The focus has not been solely on either the informants impairment nor has it been about the experiences of disablism. The sociological and the political implications of this approach are discussed in this chapter.

In the first part of the chapter, the findings are briefly summarised. The implications of the analysis of the data on the body are then discussed and what is here termed 'the private construction of impairment' are reviewed. The chapter then moves on to explore one of the major ways in which the body is made apparent to disabled people; the experience of disablement reproduced through social interaction. It is suggested that the experiences of impairment and disablement are so inter-linked that theoretical models which attempt to separate the two cannot fully capture the experiences of being a disabled person. The next two sections examine the identity claims in the informants accounts, and, in particular, what the implications of issues of identity are for the disabled people's movement and the political construction of disability. The final section puts forward a new approach to the study of disablement based on the themes that have emerged from this study, drawing particularly on the work of Honneth (1995). It is suggested that disability politics and disability studies should base their ideology on ethical rights and expectations. Interpersonal relations are as important as material relations and their importance should not be downplayed.

Summary

This section provides a brief review of the findings of this study. The key point to make about impairment in this summary is that impairments are always already social. That is, from a personal, phenomenological perspective, natural, biological or medical readings of impairment are not always relevant; impairment is always social. Impairments and impairment effects are constructed on the basis of individual experience and meaning is ascribed to them on the basis of that experience; they are not constructed, at a personal level at least, in simple, biomedical terms. What Thomas (1999) calls impairment effects cannot be seen as a biomedical or anatomical description of the body, but rather should

be seen as contingent. The presence of an impairment does not mark the body out as different, nor does it, necessarily, increase the visibility of the body to the self. Many of the informants accounts showed that impairment does not, merely by its presence, make embodiment conscious. For example, many of the actions that the informants talked about were taken without conscious reflection on either their impairment or their body. Consequently, impairment need not bias the relationship that exists between the senses and the body, as described by Merleau-Ponty (1962; 88), in favour of the body.

Impairment and its consequences have, for some of the informants, become an embedded part of their embodied being, their habitus. For these people, an impairment or a chronic condition is part of the 'taken-for-granted structures' of their life world. This relationship with the body is little different to that of other people who do not have an impairment. They carry on their lives without paying much attention to their body and their body only *dys*-appears when something happens to remind them of it. This *dys*-appearance may be the result of environmental or other barriers, prejudicial attitudes or physical deterioration which arises either as the result of changes in their impairment or other, non-impairment related conditions or pleasure or physical improvement. Provided their impairment does not cause 'trouble' then it can be, and often is, ignored.

One of the main ways that the informants were made aware of their bodily difference was through the reaction of others. Interactions with non-disabled people remind them of the social judgement that they are impaired and are seen as different. These interactions can often result in oppressive practices and it is through these interactions that disablement emerges. Disablement was one of the few shared characteristics to be found in all the informants' accounts. However dissimilar their bodies were, or whatever their life experiences had been, all faced oppression in their daily lives. In the same way that

Plummer (1975, 1991) argues that homosexuality cannot be understood separately from the society in which gays and lesbians live, so disability studies should argue that the process of disablement and the experience of being a disabled person within that society cannot be understood without exploring the reactions of that society to disabled people. Whilst it may be true that all disabled people have an impairment that arises as a result of a biomedical condition, individual reactions of the informants to their impairment do not reside in the impairment *per se*, but rather in the reactions of society to that impairment.

These social judgements did not go unchallenged. At times some of the informants directly resisted the oppressive practices through challenging those who made them, whilst at other times they described oppressive social actions as the outcome of ignorance. That is, non-disabled people treated them like they did because they did not understand what having an impairment and being disabled meant. Whilst in so doing the informants were able to minimise damage to their self, it, perhaps, should not be read as a defensive strategy. The informants talked about how, over time, and through getting to know the oppressive individual they are able to displace such social practices. Disablement, at an individual and subjective level is open to challenge and can be reduced.

The shared experience of disablement did not, however, result in the emergence of disability as a common identity. Very few of the informants described themselves as 'disabled', preferring instead to locate their identity within other social roles such as husband, wife, partner, father and so on. Disability or impairment were not seen as central to their identity, many of the informants did not feel that their physicality marked them out as different from their non-disabled peers. This claim to an identity that is not based on impairment or disablement by some of the informants is hardly surprising when

taken together with what they had to say about their body. In the same way that embodiment is not described as part of a simple impaired/non-impaired dichotomy, so identity was not seen in terms of the dichotomy disabled/non-disabled. A much more fluid, dynamic, multi-factoral relationship emerged. As argued above, impairment is just a part of their life, something that they have grown used to and is not seen as a unique identifier. According to Oliver (1996; 5), one of the defining characteristics of a disabled person is that they self-identify as a disabled person. Does this mean that these informants are not disabled? This may be considered a cheap shot, in that I did not ask the informants if they thought that they were disabled, but was trying to get at their own personal identity, the taken-for-granted way that they think about themselves. But surely, if they do not think of themselves as disabled at a personal level, then they do not self-identify as disabled. The implications of this to the disability movement are discussed in more detail later.

The rejection of disability as an identifier was maintained through number of means. Through relationships with non-disabled friends informants were able to affirm their identity as not different from other, non-disabled people. The informants also used their bodies, the way that they presented themselves and the way that they constructed their home environment to present a picture of 'normality' and of 'sameness'. Some actually questioned the concept 'normality', presenting it as a social construction. These actions were not, however, taken without cost. The struggle to maintain 'normality' in the face of challenge from a disabling society impacted on the informants sense of self and could create anxiety.

Some informants did identify as disabled, or, more correctly, impaired. Impairment impacted on their sense of self. All these informants saw their quality of life as poor and

some even questioned the value of continuing their life. They created an identity that reflected cultural stereotypes of disability. In their accounts impairment was always present, it never disappeared, it did not become part of their embodied being; having an impairment was not 'normal' to them. Disability is, as these informants described it, a tragedy and they accepted the conventional, stereotypical, idea of what a disabled person should be. However, all the informants who identified in such a way talked about other problems, their loneliness, problems with their families and friends and so. It could be argued that such accounts emerged not because of the presence of an impairment, but through other factors.

The Private Construction of Impairment

The analysis of the data presented in this thesis suggests that social scientists writing on disability need to rethink issues around the body and impairment. Some of the informants accounts call into question what are often presented as self-evident, obvious and common sense typologies, what Bourdieu (1998) terms 'practical taxonomies'. The notion of an impaired body as lacking, as inadequate or as different would be rejected by many of the informants in this study. Having an impairment does not necessarily imply a difference in embodied experience. Impairment should not be simply presented as a biological condition, for, as Freund (1988) has argued, there is no strict dichotomy between the biological and the social.

This analysis was reached by taking embodiment as grounded and experienced in daily life as the starting point. Csordas has argued that 'embodied experience is the starting point for analysing human participation in a cultural world' (1993: 135). This approach to the lived body starts from the premise that the body has to be understood as the personal ground of culture (Csordas 1990). Thus, drawing upon Merleau-Ponty, embodiment can

be defined as our 'perceptual experience and the mode of presence and engagement in the world' (Csordas 1993: 135). Through such an understanding the notion of impairment and its relationship with embodiment can be recognised. In addition it allows for the concept of embodiment to be predicated upon flux and indeterminacy (Csordas 1993, Leder 1990, Bourdieu 1979, Merleau-Ponty 1970) rather than the assumption of key dichotomies, such as impaired/non-impaired or disabled/non-disabled.

It is important to point out that a few informants' accounts did not fit the conceptualisation presented above. There were some for whom impairment and their effects were not only part of their embodied experience, they dominated it. Their body was rarely absent from their discourse. Thomas (1998) has argued that it is at what she terms a psycho-emotional level that impairment effects can operate. For example, the psycho-emotional costs of living within a disabling environment or culture, or being rejected and abandoned can foreground impairment. The analysis here would seem to support that idea. Those for whom impairment was a dominant part of their lives all talked about other problems in their lives. Many of the informants talked about how, when they felt down, they became more aware of their bodies limitations. Whilst it is only conjecture, it appears that impairment effects arise not as a result of the impairment per se, but as a consequence of the wider social and relational aspects of an individual's life.

The chapter now moves on to look at some of the ways in which the body was made to *dys-appear* and discusses some of the implications of this analysis.

The Commonality of Disablement

Much of the research within mainstream medical sociology on chronic illness and disability, although written from within an interactionist or phenomenological framework, fails to locate the social experiences of disabled people within societal reactions to impairment. Whilst it claims that its focus is on the experiences of the disabled person, these are very much addressed at an individual level. As it was argued in chapter one, the focus on narrative reconstruction, biographical disruption and coping, management and adjustment to an impairment (found in the work of, for example, Bury 1997, Frank 1995, Kelly 1996, Williams 1984), tends to ignore the social environment in which disabled people live. This has, as Garreth Williams (1996; 209) acknowledges, led to a concentration on individual reactions to impairment whilst ignoring the wider social issues. In this study, by exploring what the participants had to say when they described their experiences of interaction with non-disabled people, a picture of the society in which they are located has emerged. Not only did the fluid, multi-vocal nature of the experience of having an impairment come to the fore, but such experiences were situated within a social context. By problematising the issue of impairment and examining the socially constructed nature, at a personal level, of impairment and locating such an analysis within social responses to people with impairment, the social oppression experienced by disabled people has been explored. Disablement arises through relations and what this analysis has shown is the relationships processes through which people with impairment conduct their lives.

Many of these practices were described by the informants. However, some practices that discriminate against disabled people, such as the role of the state, class and other sociological abstractions, may be missing from the research participants' accounts. This absence is important to acknowledge and is a major weakness of the research approach

used in the study. Institutionalised discrimination exists, as Barnes (1991) and others have clearly shown; there is a social structure and this structure defines inequalities and gives rise to oppression. However, such material analyses do not show how such processes are played out in the lives of disabled people and these social processes are embodied. Indeed disablement is a distinctly embodied experience in that not only is the body engaged in such practices, it is the object of those practices. This study has shown the way that impairment can be used by society to discriminate against disabled people and the way that this discrimination is enacted in their everyday lives and becomes part of the everyday reality of being a disabled person. The societal reaction of hostility and oppression can play a crucial role in bringing about an exaggerated concern with impairment and a potential for polarisation between disabled/non-disabled people. In addition, by documenting the way in which oppressive social practices are resisted, as this study has, disabled people can be shown to be active agents and not painted as passive victims of either their body, as in medical sociology accounts, or of society, as in disability studies accounts.

Further, the analysis suggests that impairment and disablement are linked and that calls for a social model of impairment to exist alongside a social model of disablement, by, for example, Oliver (1996), are not sustainable. This is not to suggest that impairment causes disablement, but that the social ascription of impairment is a pre-requisite for disablement to exist¹. Disablement, whilst not caused by impairment, is reproduced because of impairment and disabling practices serve to remind disabled people that they

¹ If this is not accepted, then it could be argued that anybody who faces discrimination is disabled, whether this discrimination arises as a result of class, ethnicity, gender, age or sexuality. Whilst there are obvious links between these various forms of discrimination and the exploration of such links is useful, there is still a need for a specific term to describe the experiences of oppression faced by people who are impaired. This need not mean actually having an impairment but can include being believed to have an impairment, previously having had an impairment or having a condition that is socially believed to be an impairment.

have an impairment. The two interact, impairment and disablement are, in experiential terms, inseparable. Relationships are constituted through impairment and disablement. Disablement, as Hughes and Paterson (1999) argue, produces impairment, whilst at the same time, on an intersubjective level, societal reaction to impairment produces disablement which reproduces impairment. They are not, however, simply 'glued' together, but, the relationship between the two oscillates. At certain times it is impairment effects that brings the impairment to the fore whilst at others it is disablement produced through societal reactions to impairment, which can themselves serve to amplify or create impairment effects.

The commonality of the experience of impairment or disablement does not, however, serve to act as a bond between the participants. There appears to be no sense of group identity built up on the experiences of being a disabled person. Their shared experiences of social ostracism, the accordance of low status, their denial as full partners in interaction and their lack of rights have not served to politicise many of these informants or to encourage them to bond together with other disabled people so as to form a political unit to challenge, on a group basis, the social oppression that they face. Such action is taken instead at an individual, subjective level.

Honneth (1995) argues that disrespect can be the starting point for politically motivated action, leading to what he terms a 'struggle for recognition'. Disrespect, according to Honneth, comprises humiliation, disenfranchisement, insult and physical abuse, all processes to which the informants report that they are subjected to, whilst recognition is seen as the ascription of a positive status. So he writes:

..the negative emotion accompanying the experience of disrespect could represent precisely the affective motivational basis in which the struggled for recognition is anchored (*op cit* 135)

However, for any such action to take place, those who face disrespect must identify as a group. It is to this issue that this discussion now turns.

The Personal Construction Identity

Oliver (1990, 1996) has claimed that the new disability politics that has emerged through the social model has seen a move away from self-help organisations *for* disabled people to self-organised, overtly political groupings *of* disabled people and controlled by disabled people. These, he suggests, constitute ‘a new social movement’ as described by Touraine (1981). So Oliver writes:

These movements have been seen as constituting the social basis for new forms of transformative political action or change. These social movements are ‘new’ in the sense that they are not grounded in traditional forms of political participation through the party system or single issue pressure group activity targeted at political decision makers. (1990: 113)

However, as Touraine (1981) makes clear, for new social movements to be effective, participants must self identify as a member of a collectivity. The accounts presented in this thesis seem to suggest that, for many disabled people, such a collective is failing to coalesce.

Given the social oppression that the informants describe, which is based on the fact that they are disabled people, it is understandable that many of the informants choose not to identify as a disabled person. In the hierarchy of social values prevalent within British society, which accords little or no status to disabled people, describing oneself as disabled cannot be seen as a positive step. There is no social status to be gained for 'coming out' as disabled. Indeed the very term 'coming out' may be inappropriate when used in conjunction with disabled people. The classic definition of 'coming out' is given by Simon and Gagnon as

the point in time when there is self recognition as a homosexual, and the first major exploration of the homosexual community (1967; 181).

For disabled people, there is no equivalent of the homosexual community². Neither do disabled people share a common religion, common political beliefs, a common social class. There are differences along the lines of gender, age, ethnicity, sexuality, region, partnerships and health. All these serve to challenge the idea of a unanimity of a disability collective. There are no rules about what it takes to belong to 'the disabled community'. Whilst it could be argued that all disabled people share one essential characteristic, that is they have an impairment, the idea of a common identity based on the presence of that impairment, compelling as it may be, is not sustainable.

² It could be argued that the only communities that disabled people share are those that have arisen as a result of disabling practices such as segregated schooling, housing policies, and Adult Training Centres. Further, the increasing number of disabled people now living outside of hospitals and homes run by organisations such as the Leonard Cheshire Foundation, the move to inclusive education and the increasing numbers of disabled people living in their own homes will, if anything, dilute what little sense of commonality there is that exists between disabled people.

The analysis of data presented here would seem to suggest that a social movement which aims to represent disabled people, and bases its credibility on the fact that it does so, as many of the organisations of disabled people do, rests on an unreflexive acceptance of the distinction disabled/non-disabled. It is not that these informants are rejecting the social model of disability in favour of the medical model, they are merely downplaying the significance of their impairments as they seek to access a mainstream identity. This refusal by some of these informants is often portrayed as the result of 'internalised oppression' or 'false consciousness' by radicals within the disability movement (Shakespeare and Watson 2000). Yet, surely all that these informants are trying to do is to challenge the idea of normality and refuse to be categorised on the basis of bodily difference.

Gilroy (2000) has recently argued that much of the writings on 'race' are based on what he terms 'anthropological distinctions' (p31). He argues that the concept of 'race' as a unifying concept is a relatively recent development and that the use of the body as a signifier for a particular culture is dangerous. Culture should be lived not owned. A reliance on bodily difference as a marker for membership of a particular group can serve to reify that difference. It may be argued that the disabled people's movement and its academic supporters are guilty of such reification, and it is the disabled people who do not identify as disabled that are taking the more radical approach. Whilst the proponents of the social model argue that they are campaigning for a society in which disablement does not exist and impairment is seen merely as a biological descriptor of the body, the assertion that a disabled person is one who has an impairment and self-identifies as disabled suggests a typology that is always already based on difference. The essentialist nature of Oliver's (1996; 5) definition of a disabled person runs counter to many of these informants' accounts.

Any political position which rejects a notion of sameness is open to such a charge of essentialism. For example, Thomas (1999) has pointed out the essentialist nature of much of Morris' (1991, 1996) work. Morris, throughout much of her work, refers to disabled people as 'us' and non-disabled people as 'them'. Similar language can be found in the work of Crow (1996) and French (1992). Yet few of the informants in this study would seem to endorse such distinctions. Indeed some of the informants described how they had moved from such a position in the past to their current one in which they reject any notion of difference. Interestingly, those that described themselves as different tended to be those who would appear to be the least likely to be politically active and campaign for civil rights for disabled people. Their identity as a disabled person was based on a negative³ assessment of what it is to be a disabled person.

The wholesale acceptance of disability as an identifier found in some of the accounts should not be seen as surprising given the prevailing orthodoxy within British society to categorise people with an impairment as disabled and as different. What should be seen as surprising are the people who reject that label. However, where does this leave disability politics? If disability studies and the disabled people's movement cannot rely on self-identity as a marker, how can it progress?

Corker (1998) and Shildrick and Price (Price and Shildrick 1998, Shildrick and Price 1996, Shildrick 1997) have, as previously discussed in chapter two, suggested a need for an approach that rejects a disability identity as a foundation for disability politics. They argue that a politics of identity is premised on a modernist concept, tied as it is to unitary,

fixed, essentialist conceptions. Political strategies that rely on identity merely serve to reinforce the social order: they propose that identity be seen as an outcome of discourse and representation. It is heterogeneous, shifting and tenuous. What is needed instead, they argue, is a direct challenge to the prevailing cultural categories that are used to delineate people. The analysis of the data in this study would seem to support that contention. By not identifying as disabled and rejecting an identity based on difference this is precisely what some of the informants in this study are doing. However, in Shildrick and Price's work it could be argued that whilst they reject the notion of identity, the idea of difference is still central to their theorising. What some of these informants are arguing is that they are not different.

Having looked at the implications of the informants accounts of identity for disability studies and disability politics, this chapter now moves on to examine the implications of the informants accounts on how they maintained their identity.

The Intersubjective Nature of Identity and Implications for the Political Construction of Disability

That the identity of the informants was constructed through intersubjective relationships, that it emerged through process rather than as a result of membership of a category and that it was not bound by fixed attributes has been a central emergent theme from this analysis. The central question that this raises however, is how is this process to be understood and what is its relationship to ideas around difference, structure and agency? How is it that many of these informants reject notions of difference?

³ Whilst the use of the term 'negative' could be criticised for its normative assumption of what is good and what is bad, normative standards have to be applied in work that attempts to propose a progressive analysis of disability.

Identity, as discussed above, has become central to the disability movement. The idea of a collective identity has emerged through ideas around new social movements and other political developments. Identity is not seen as a process emerging through social interaction, but as a badge, as a marker without which one cannot truly be considered disabled. As Gilroy, in his monograph on 'race', puts it:

Identity is latent destiny. Seen or unseen, on the surface of the body, or buried deep in the cells, identity forever sets one group apart from others who lack the particular, chosen traits that become the basis of typology and comparative evaluation (2000; 104)

Yet, as is clear in the data analysed in both chapters six and seven, identity emerges through interaction. The exploration of identity discussed in this thesis has allowed an analysis of the interplay between subjective experience and the cultural and historical settings in which such subjectivities are formed. The informants were active in social relations, in creating their own identities. Those informants who were located within what they felt to be secure social networks were able to construct what could be termed a mainstream identity rejecting an identity constructed through difference.

It is through individual agency they are able to make a choice and challenge identities based on fixed, essential characteristics. They are able to challenge societies reactions to their impairment and refuse to see their identity as located in the body. The informants are able to reject the rejection of others through their own experiences, their own actions, through the affirmation of important and significant others and through intersubjective recognition, regardless of the fact that this may only be partial. Whilst identity is based on the recognition of others, it seems, from this analysis, that one can select who those

others are, whose views are accorded status. By deriding the views of those who do not recognise the self as seen by the self and writing off their comments as being the product of, for example, ignorance, feelings of what Honeth (1995) terms disrespect can be avoided. The informants who identified as disabled and who fulfilled cultural expectations of what a disabled person should be, 'tragic victims', were those who described themselves as lonely, who were not connected and had few 'webs of interlocation'.

However, these actions are private, they do not, nor can they by their very nature, produce wide-scale social change. What social change they do produce is local. It is confined to the disabled person's immediate contacts and there is no way of knowing if the conversions that they achieve have any effects on those who they meet beyond their interaction with that individual. They cannot be generalised beyond the circle of primary relationships. What is needed, in terms of disability politics is an approach that enables the connection between private experiences and the aspirations of the disability movement.

Honneth (1995) has argued that whilst Marx himself based his economic and political theory on his explorations of the experiences of the proletariat and linked the emerging political movement to assaults on their dignity, this has not been reflected in the emerging conceptual framework employed by many Marxists. He writes:

...the internal connection that often holds between the emergence of social movements and the mortal experience of disrespect has, to a large extent been theoretically severed at the start. The motives for rebellion, protest and resistance have generally been transformed into categories of 'interest', and these interests

are supposed to emerge from the objective inequalities in the distribution of material opportunities without ever being linked, in any way, to the everyday web of moral feelings. (*op cit* p. 161)

This, it could be argued, is precisely what has happened to the disabled people's movement. The social model of disability owes its origins to Hunt's (1966) edited collection *Stigma: The Experience of Disability*. Hunt went on to become influential in the formation of UPIAS and in setting out its manifesto, *The Fundamentals of Disability* (1976). What is now called the social model emerged through the experiences of a small, but influential, group of disabled people (Campbell and Oliver 1996). From this start the social model has become the 'sacred cow' of the disability movement. Alternative approaches are rejected (see Barnes 1998, 1999).

Yet the social model emerged in a very different society to the one that disabled people now live in. As already mentioned, many more disabled children are now educated in mainstream schools; many more disabled people live in their own homes; disabled people are less likely to live in long stay institutions; they are more likely to live in the mainstream, many more disabled people are accessing further education (Thompson and Ward 1996); higher education is gradually opening its doors to disabled people and the institutions are now compelled by law to produce Disability Statements; the passing of the Disability Discrimination Act, despite its inadequacies, is a major step forward in that discrimination against disabled people is now legally recognised (O'Dempsey and Short 1996); the proposed expansion of the DDA to cover education may have a major impact on the educational opportunities open to disabled people; many more buildings are now accessible and legislation will ensure that all new buildings are. Further, advances in medical science have already reduced the impact of some impairments on the lives of

some disabled people, and despite some concerns on the direction that these might take, there is hope for more improvements in the future (Shakespeare 1999). All this has served to create a very different environment in which disabled people now live. This is not to suggest that disabled people no longer face discrimination or oppression, as the analysis in this study shows, oppression is still very much part of the everyday life experience of being a disabled person. As Shakespeare and Watson (in press) argue, a model which was developed in the early 1970s no longer seems as useful at the beginning of the twenty-first century. Bailey and Hall put this point eloquently:

It is perfectly possible that what is politically progressive and opens up discursive opportunities in the 1970s and 1980s can become a form of closure – and have a repressive value – by the time it is installed as the dominant genre.... It will run out of steam; it will become a style; people will use it not because it opens up anything but because they are being spoken by it, and at that point you need another shift. (1992, 15).

In addition, this study would suggest that the social model, by seeking to fit the complex actuality of lived experience into narrow formal categories and reducing everything to material social barriers has created a distance between theory and disabled people's own experiences. Too much is left unexplained. The social model produces generalisations which seeks to explain everything and to homogenise the diversity of disabled people's experience. Many of the informants in this study wanted to be 'real' people, to discard the mask of disability, to be neither seen as a tragic victim nor a powerful disability activist, but just simply a person located within their own social network, adopting roles and identities that they choose with their own talents and inadequacies.

How then does the disability movement take the ideas that have emerged from this analysis forward and present a new framework through which disability can be theorised? It is to this that this chapter now turns.

Concluding Remarks: Towards a New Political Construction of Disability

To recap; so far this chapter has suggested that impairment, from a personal perspective, needs to be seen as a social construct; that all the informants in this study face discrimination in their everyday lives and that this discrimination serves to make the body *dys*-appear; that impairment should not be presented as the biological and disablement as the social; that many of the informants do not identify as a disabled person and that this poses problems for a movement which is premised on the idea of self-identification as a disabled person for its political potency; and that many disabled people are able to access a non-disabled identity as a result of interpersonal relationships.

Further, throughout the thesis the informants' accounts have exposed the artificially created disjunction between the private, personal experience of impairment and the public, social experience of disability. The analysis has shown the complexity of disability, its variability, its contingent nature, its historicity, its fluidity. As Shakespeare and Watson (in press) argue, disability is the quintessential post-modern concept. It sits at the intersection of biology and society and of agency and structure. It cannot be described as any one thing, it is a multiplicity, a plurality. How then is this analysis to be made politically operational? Does a more nuanced, more adequate explanation of the relationship between impairment, disablement and identity add anything to a public understanding of disability? Will it contribute to the reduction of the oppression of disabled people? Is the radical rhetoric of the social model, the appeal of the 'big idea', the meta-narrative that it provides, despite its obvious lacunae which have been

highlighted here and in other work, such as that of Corker (1999), Shakespeare (1994) and Hughes and Paterson (1999), so attractive that attempts to reform or re-conceptualise it are only of academic value? One of the obvious strengths of the social model is its simplicity; disablement is the fault of society and the consequence of impairment, therefore change society and not disabled people. The analysis in this study suggests a more complex, more intricate analysis is needed to capture the full range of the disability experience. However, with complexity comes the potential for confusion, and the potential for distancing disabled people from ownership of theory (Corker 1999). This section considers two options for a more nuanced understanding of disability.

Corker (1999), drawing on Oliver's (1996; 52) assertion that the social model should not be seen as a social theory of disability but as one strand of it and that there is a danger in trying to take it further than it is meant to go, argues that what is needed is an approach rooted in discursive strategies to complement the structural analysis favoured by the social model. She writes that it is the relationship between 'the cultural/structural and the material/discursive' that should form the basis of theorising (p639). This is seen as important because:

..the addition of this paradigm would... open up political discourse to issues of language and difference and their relationship to the unequal distribution of knowledge. It would also allow us to address more fully the question of disabled people's social agency, and the sticky issue of attitudes and discriminatory language that cannot be explained within materialism alone (*op cit* p. 640).

Through such an analysis, disablement would emerge not as the collective experience of oppression, as in the social model, but through the relationship between impairment and

oppression. It therefore follows that if either oppression or impairment are removed from the equation, then disablement itself goes. This, it could be argued, is what many of the informants in this study do. They reconfigure both impairment and oppression and in so doing, do not see themselves as disabled. They reject the notion of disability as a 'universality', disabled people are not an homogenous group. It also allows for the inclusion of other types of oppression. If disablement alone is the focus of attention, all other kinds of oppression can become marginalised, hidden or repressed. So, in such an analysis the differences between genders as described by the informants in relation to expression of sexuality and relationships can emerge.

However, much post-modernism renders any application of the concept of social justice as problematic (Harvey 1993). If there are no universal truths, there is no concept of universal justice. There are no normative standards to distinguish between the progressive and the reactionary, indeed these latter two terms cannot be employed. Social justice is itself situated, contingent, the concept can be deconstructed. So Harvey writes:

There are only particular, competing, fragmented and heterogeneous conceptions of and discourses about justice which arise out of the particular situations of those involved. (1993; 98-99)

There are no foundational appeals to the common good, as such concepts are no longer seen as carrying rhetorical authority.

The discursive turn as suggested by Corker (1999) denies, through its rejection of a universal disabling condition, an appeal to a universal social justice. Yet, at the same

time, she is attempting to promote resistance to the cultural conditions which shape and cause disablement. These cultural conditions are, in the main, general and systematic. As the analysis in chapter four showed, they are embedded in the lifeworld of disabled people. Regardless of the fact that they are reconstructed by the informants at a local, personal level, they are a universal condition of disabled people. They all face discrimination, and if a strategy is to be developed to tackle this discrimination, then it can only be successful if a normative sense of justice using universally valid systems is employed (White 1991). Only through applying such a normative standard is it possible to develop and work towards a desired end, namely the removal of disabling barriers and attitudes. Post-modernist approaches cannot engage with the meta-narratives which dominate the lives of disabled people. The wider political and economic powers that are manifest throughout capitalist systems go unchanged. As the old joke goes 'How many post-modernists does it take to change a light bulb? Post-modernism changes nothing'.

Oppression, despite its deconstruction at a local level by many of these informants still exists. It is a 'reality' for these informants. The section in chapter seven that documents the impact of the struggle that the informants go through as they negotiate their identity clearly shows this. Further, their identity construction is fragile, they can be reminded that they are different and when this occurs it can, for a short period, damage their sense of self. Note for example the fact that one of the informants who was physically assaulted refused to talk about it as it was too personal and upsetting. Also, the fact that, at times the body can *dys*-appear suggests that impairment also exists and through that realisation, disablement can again appear.

To turn this into a political strategy, then, requires a means by which this hurt engendered by private experiences of injury are channelled into political actions that accord with the

political aspirations of the disabled people's movement. A language needs to be developed which allows for the forming of a model of disablement through which these feelings of hurt can be seen not as individual assaults, but as part of a systematic attack which can be shown to be typical for disabled people as a whole. The social model, with its denial of the importance of experience and its emphasis on material relations fails in this in many ways. Disablement is not, at an individual level, perceived to be an attack on material opportunities. Disabled people are not competing for scarce goods in a market place. Rather, disablement is felt as the outcome of the withholding of social and cultural recognition, and it is this that should form the basis of the social struggle.

Honneth (1995) argues that it is important to reconcile the individual as well as the collective dimensions of political struggles. For him, self-confidence, self-respect and self-esteem provide the possibility of identity formation. This works at three levels; relationships, legal rights and solidarity. In the later term, Honneth is not referring merely to solidarity within groups, but, importantly, between groups. Through relationships, self-confidence emerges; through rights, a sense of personal dignity emerges; and through solidarity, self esteem. Denial of relationships can result in a loss of physical integrity, denial of self-respect, social integrity, and denial of self-esteem can damage honour and dignity. It is a need for recognition that drives minority communities to mobilise for change and it is the negative emotional reactions that result from the experiences of being denied recognition that form the motivational basis for social struggle. He cites the work of the Marxist historian E. P. Thompson (1963) who suggests that social rebellion requires more than economic hardship. It requires a violation of the accepted moral consensus, a denial of what are felt to be the moral expectations of people within that community, that is recognition.

There is a material element to Honneth's work, in that he clearly recognises the need for legal protection and civil rights. However, rather than seeing this as an abstract, unconnected concept, Honneth shows how the impact of rights can have an interpersonal, subjective element:

Since possessing rights means being able to raise socially accepted claims, they provide one with a legitimate way of making clear to oneself that one is respected by everyone else (1995; 120)

Through such an approach he manages to present a rights based discourse at a personal level. Further, in his arguments on solidarity he is able to articulate why such an approach is important, again at an intersubjective level:

The more successful social movements are at drawing the public's attention to the neglected significance of the traits and abilities which they collectively represent, the better their chances of raising the social worth, or indeed standing, of their members (1995; 127)

Much that Honneth says seems to fit with the analysis of the data presented here. Those informants who were in or had stable, secure, social relationships, who felt that they were valued members of society, who recognised themselves as such, and felt some sense of solidarity with other members of their community presented with a strong, autonomous, individuated identity. Whilst, conversely, those who felt alone and abstracted from the mainstream gave an account of their self as one that is damaged. As far as a move to political action is concerned, moral indignation is absent in both groups. In the first group, their own private experiences serve to counter their struggle for recognition in

interactions outside of their immediate circle. That is, assaults on their integrity can be ignored because of the bolstering effects of others. In the second group, the violations go unchallenged because they do not challenge their own normative expectations of what it is to be a disabled person. This places the disabled people's movement in a quandary. Those who would be most likely to be active within the disabled people's movement, in that they are active social agents, are those who are least likely to face a struggle for recognition, whilst those who face this struggle tend not to show such active agency and would appear to be the least likely to take political action.

What is therefore needed then is a political activism that is founded on ethical rights and expectations. The disabled people's movement, at the same time as focussing on, for example employment legislation and environmental access, should be placing emphasis on interpersonal relations as it is through such relations that people experience recognition as active, capable social agents or find such recognition denied. By focussing solely on the material, a distance is created between disabled people's experiences of disablement, which occur at the interpersonal, and the political response. Through a focus on both legal and interpersonal relations the possibilities are opened up for a historically situated transformation of the social relations of disabled people.

What then would be the practical elements of such an approach. First, disablement should be challenged at an interpersonal level. Impairment and disablement are not dichotomous; one cannot be ascribed to the biological or personal and the other to the social. They are both experienced at a societal level and become apparent through interaction. It is this interaction that should form the basis of any challenges to disablement. These relationships are constructed through impairment and disablement. In terms of impairment, the disabled people's movement should seek to challenge and

overturn essentialist notions of normality. This is not a new idea, but draws on the work of Sutherland⁴, who writes:

A more radical approach is needed: we must demolish the false dividing line between 'normal' and 'disabled' [meaning impaired] and attack the whole concept of physical normality. We have to recognise that disablement [impairment] is not merely the physical state of a small minority of people. *It is the normal condition of humanity.*" (p 18, italics in original).

This is the way that many of these informants lead their lives; impairment is, for them, normal. It is not seen as an identifier. It could be argued that academics in disability studies and disability activists ponder on the issues of disablement and impairment far more than most disabled people⁵. In the same way that it was suggested earlier that medical sociology, because of its normative stance, reifies impairment, so too does disability studies. Neither approach the experiences of having an impairment from the taken-for-granted, lived, embedded perspective of many disabled people. Disability studies and the disabled people's movement have nothing to fear from the body, provided it is approached in such a manner as described in this study.

Second, meta-narratives need not be forsworn. Disabling social relations are everywhere and, as Fraser and Nicholson (1990; 34) argue in relation to sexism, disablism is deeply embedded in contemporary society. Disabling societal macro-

⁴ Zola (1989), Hughes and Paterson (1999) and Watson and Shakespeare (1995) have all made similar points to this.

⁵ This might be seen as unfair, in that the role of academics is to analyse, but such analysis should be grounded in the experiences and perceptions of disabled people and should reflect what they themselves feel about themselves.

structures need to be analysed and challenged. However, these theoretical responses must be situated in specific social, cultural and historical contexts. There is no unitary notion of either disabled people or a disabled person. Impairment and disablement are but strands of a complexly constructed social identity. Age, gender, ethnicity, class and sexuality, among many others, are all of equal important and can create differences between disabled people. Whilst the acknowledgement of such differences could be seen as a threat to the internal solidarity of the disability movement, without such acknowledgement it will be difficult to build alliances with other movements.

Third, disability studies and the disabled people's movement should engage in more ethnographic and qualitative research so as to present a picture of the 'realities' of being a disabled person in the early 21st Century. That is, through stories and narratives of and by disabled people, disabled people will be enabled to express the heterogeneity of their lives, the fluid, situated and contextual nature of both disablement and impairment and the meaning of disability and impairment and through this to develop a value system that represents the diversity of the disability experience. Examples of this sort of approach, in addition to this project, include the work of Shakespeare et al (1996) on sexuality and disability which documents, for the first time, disabled people's own views on sex and their sexuality; and the work by Davis et al (2000) and Prestley et al (1999) on disabled children. This work, by presenting disabled children's own stories from their own perspective, make possible new forms of distinctive identities which are not based on essentialist characteristics. Work in the popular media also comes into this category, so for example the BBC television series *The Disabled Century*, and Peter White's Radio 4 series *No Triumph, No Tragedy* present new images of disabled people that challenge cultural stereotypes. This work, as well as challenging disabling images, establishes disabled people as active agents, as subjects rather than objects and allows disabled

people to see themselves as a member of a social group who can accomplish things and whose worth is recognised by all members of society.

This focus on ethnography can create problems. As Connell (1997) argues in respect to ethnographic work on sexuality, there is a danger that emphasis can be placed on what distinguishes one group of people from another, in this case disabled people from non-disabled people, rather than what links them. This can be avoided provided similarities are highlighted, as this study has tried to do and that disabled people are included in other ethnographic studies focussing on, for example, sexuality, ethnicity, age or gender.

Through this tripartite approach a more comprehensive and inclusive social theory of disability can emerge. This approach mirrors that of Zola (1994), who, just before his death, argued for a plurality of approaches in the study of disability. Further, the adequacy of current theory to support the actions of the disabled people's movement can be ascertained, for if these campaigns are to be effective they must work with rather than against disabled people's beliefs. By the use of studies giving primacy to the views and experiences of disabled people an understanding of commonly held ideas about the nature of disablement and the experiences of having an impairment that are historically situated can emerge. The question of whether research is or is not emancipatory becomes redundant and is replaced with the question, is this work based on the views and experiences of disabled people and has it come from a perspective that rejects normative values on the impact of impairment and disability on people's lives? If the answer to this is yes, then the work is emancipatory in that it will provide further evidence for the creation of solidarities both within and between groups. Through such an analysis an understanding of disability can evolve which is grounded in the social and cultural context of living with an impairment. Disability will be seen not as either the product of

an individual trait, the impairment, nor as simply a social product, but as a fluid multiplicity which is subject to complex structural and interactional factors.

Disability should not be studied from either an exclusively political approach, as found in the social model, or an academic approach confined to anthropology and sociology. Both approaches are needed so as to allow an analysis of the oppression faced by disabled people and the social experiences of living with an impairment. What the proposal here is suggesting is just such a plurality, but importantly, one that is grounded in the experiences of disabled people and that disabled people can themselves connect with. It provides the possibility of moving beyond boundaries and reinventing disability politics as a democratic movement.

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